

# **Chronic Pain in Afghan Immigrant Women: An Exploratory Mixed Methods Study**

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for a Master of Science Degree  
in the Department of Health Sciences  
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Saskatoon

By

Julie E. Penner

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## Abstract

**Purpose:** The purposes of this study were: (a) to describe the physical and mental health status of Afghan immigrant women in one Canadian city; (b) to construct an Afghan cultural model of pain (experience and management) using interview data and available literature; (c) to explore the experience of chronic pain and its management among Afghan immigrant women, both culturally and individually; and (d) to identify potential barriers to chronic pain management for both Afghan immigrant women and their health care providers.

**Methods:** This study has two parts; questionnaires were used in Part 1, and semi-structured interviews supplemented by three short questionnaires were used in Part 2. Interpretive description methodology using thematic analysis and conceptual mapping was used for analysis of interviews in Part 2.

**Results:** SF-36 responses ( $n = 9$ ) in Part 1 suggested that the physical health status of the Afghan women was better than their mental health status. Health sciences literature and interviews with 6 Afghan immigrant women and 1 healthcare professional were used to construct cultural models of pain experience and pain management. Findings indicated that Afghan immigrant women who experienced and managed their chronic pain within their cultural model did so holistically across multiple factors: environmental, spiritual, biological, and psychological. However, each individual internalized their cultural model of pain in varying amounts. Barriers in healthcare access that prevented Afghan immigrant women from managing their pain well included: (a) different cultural perspectives between Afghan immigrant women and healthcare professionals regarding how pain is experienced and managed; and (b) communication difficulties between healthcare professionals and Afghan immigrant women.

**Significance of Findings:** Cultural perspectives on pain experience and pain management influence treatment expectations and pain management. Differences in cultural perspectives are a barrier in healthcare access that prevents Afghan immigrant women from managing their pain well. Addressing the differences in perspective identified in this study will increase understanding for healthcare professionals as they work together with Afghan immigrant women patients, thereby improve communication and reduce barriers to pain management.

*Keywords:* chronic pain, culture, pain management

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## **Dedication**

I dedicate this work to the women of this study; may they experience peace and healing.

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### **List of Abbreviations**

CNS	Central Nervous System
EDA	Epidural Analgesia
EOI	Evaluative Overall Intensity, a component of the SF-MPQ
FPS-R	Faces Pain Scale - Revised
IASP	The International Association for the Study of Pain
I-SF-MPQ	Iranian Farsi translation of the Short Form McGill Pain Questionnaire
MCS	Mental Component Summary, a component of the Short Form 36 Health Survey
NBS	Norm Based Scores, used in the Short Form 36 Health Survey to compare an individual's score to national averages
PCS	Physical Component Summary, a component of the Short Form 36 Health Survey
PPI	Present Pain Intensity, a component of the SF-MPQ
PRI	Pain Rating Index, a component of the SF-MPQ
PTSD	Post Traumatic Stress Disorder
REB	Research Ethics Board
SF-36	Short Form 36 Health Survey
SF-MPQ	Short Form McGill Pain Questionnaire
VAS	Visual Analogue Scale

## Glossary

Term	Definition
Acculturation	“A process that is executed by an agentic individual... after meeting and encountering a cultural community that is different from the cultural community where he or she was initially socialized.” (Chirkov, 2009, p. 106).
Afghan cultural model of pain	The Afghan cultural model of pain, for the purposes of this study, is described as the way that the Afghan community views pain. This includes the meaning and expression(s) that the community attributes to painful experiences, and the way that their families and community deal with pain.
Allah	Muslim and Arabic word for God (Thompson, 1992)
Chronic Pain	Chronic pain, for the purposes of this study, is described as pain, or bodily hurt, that has lasted for six months or greater. Chronic pain is felt from week to week. It may be there all the time, come and go from day to day, or get worse or better based on activities. Chronic pain has significant impact on quality of life.
Culture shock	An experience of “intense and usually prolonged emotional upheaval”, which immigrants experience when they “realize how ‘strange’ their adopted new culture is and how difficult it is for them to adjust to it” (Krippner & McIntyre, 2003)
Disease	“A condition of abnormal vital function involving any structure, part, or system of an organism” (Mosby’s Pocket Dictionary, 2002)
Encultured informants	“Individuals who know the culture well and take it as their responsibility to explain what it means” (Spradley, 1979, p. 47, as cited in Rubin & Rubin, 2005, p. 66)

Term	Definition
Holistic	“As a unity; not as separate parts” (Thompson, 1992)
Illness	“An abnormal process in which aspects of the social, physical, emotional, or intellectual condition and function of a person are diminished or impaired, compared with that person’s previous condition” (Mosby’s Pocket Dictionary, 2002)
<i>Jin</i>	Evil spirits, believed to cause physical ailments (Aziz, 1999)
<i>Nazar</i>	Evil eye, when someone looks at another with bad thoughts or intent. If sudden harm or illness comes to a person who is doing well, it is believed that the evil eye may be a cause for the harm or illness (Aziz, 1999)
Pain	<p>For the purposes of this study, pain is defined as somatic hurt, bodily hurt, or physical hurt. As discussed in the literature review, somatic pain can be greatly influenced by or originate from emotional or mental components. However, the term “physical” means that this pain is experienced in the body.</p> <p>IASP pain definition: “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (IASP, 2011)</p>
Pain as multifactorial	When this thesis uses the term multifactorial to describe pain, this means that multiple factors, or agents, contribute to the pain experience
Pain management	For the purposes of this study, pain management includes the ways that Afghan women attempt to cope, reduce, or eliminate their pain
Refugees	People who escape persecution in their home country over matters of race, nationality, political orientation, or religion (Lipson & Omidian, 1997, as cited in Aziz, 1999)



Term	Definition
Self-efficacy	<p>A person's perceived capability to control his or her own functioning and the events that impact his or her life (Ajzen, 2002)</p> <p>A person's beliefs about his or her ability to coordinate skills and "attain desired goals in particular domains and circumstances" (Maddux, 2002, p. 278)</p>
Somatization Disorder	<p>"Psychiatric disorder characterized by recurrent multiple physical complaints and symptoms for which there is no organic cause.... The symptoms vary according to the individual and the underlying emotional conflict" (Mosby's Pocket Dictionary, 2002)</p>

## Basic Transcription Symbols

Transcription symbol	Description
(word)	Possible hearing of word
(.)	A short pause
<u>word</u>	Word is stressed

(Silverman, 2006, Appendix)

## Chapter 1

### Introduction

Afghan immigrant women in Canada form unique communities with unique support systems and needs. In the past, many of their families were exposed to trauma and loss in Afghanistan. In their more recent past, Afghan immigrant women have experienced a great transition as they have immigrated to Canada.

Immigration to Canada has been a difficult process for Afghan women. Many of these women strongly value their cultural traditions. They feel that they were torn from their home country as a result of unfortunate conditions in Afghanistan. Moreover, they have experienced many changes to their identities, roles, and responsibilities as they have immigrated to Canada; this has exacerbated an already high prevalence of poor physical health, anxiety, and depression among Afghan immigrant women (Aziz, 1999). Their health has suffered as a result.

The literature has uncovered a need for research regarding chronic pain and its management among Afghan immigrant women. Afghan women have been identified to be strong and resilient in the face of great obstacles (Aziz, 2011; Brodsky, 2011; Macmakin, 2011). However, characteristics of this population established in the literature, such as exposure to trauma, oppression under the Taliban, low control over the immigration process, difficulties with immigration, inadequate health support, high prevalence of mental health problems, low levels of education, and refugee status (Lipson, 1991; Lipson, Omidian, & Paul, 1995; Aziz, 1999; Amowitz, Heisler, & Iacopino, 2003; Omeri, Lennings, & Raymond, 2006; Dossa, 2008; Sartip, 2010) suggest that chronic pain might be a problem for Afghan immigrant women. Nevertheless, documentation that addresses their chronic pain from a medical perspective is scarce.

Most healthcare professionals in Canada know very little about Afghan immigrant women and their health needs. They do not know how Afghan immigrant women experience or manage their chronic pain. As a result, healthcare professionals may not know how to provide pain treatment strategies for Afghan immigrant women that are practical, culturally appropriate, and effective.

### **1.1. Purpose**

The purposes of this study were: (a) to describe the physical and mental health status of Afghan immigrant women in one Canadian city; (b) to construct an Afghan cultural model of pain (experience and management) using interview data and available literature; (c) to explore the experience of chronic pain and its management among Afghan immigrant women, both culturally and individually; and (d) to identify potential barriers to chronic pain management for both Afghan immigrant women and their health care providers.

### **1.2. Disciplinary Perspective**

Disciplinary orientation influences what in research is observed and how it is interpreted. According to Thorne (2008), disciplinary orientation is “an essential aspect of the research forestructure and grounding” (p. 68). In this study, the research design, analysis, and write-up came from the perspective of the discipline of physiotherapy. My disciplinary perspective as a physiotherapist has influenced what I chose to study, the questions that I asked, what I heard and observed, and the analytical processes that were completed through the course of this research. Although thesis findings may at times be oriented toward the discipline of physiotherapy, I believe this research is also relevant to other healthcare professionals.

## Chapter 2

### Current State of Knowledge

The literature review has been separated into four major topics and within each topic moves from general to specific. The four topics are:

1. Socio-cultural and political influences on health in Afghanistan
2. Impact of immigration on health
3. Immigration and access to healthcare
4. Pain and immigrant health

This literature review is not meant to be an exhaustive review. It is included to provide context for the study and to demonstrate the gaps related to our understanding of pain and pain management in Afghan women who have immigrated to (or sought refuge in) Canada.

#### **2.1. Socio-Cultural and Political Influences on Health in Afghanistan**

**2.1.1. General.** Although unrest and political instability are a part of Afghanistan's long history, most of today's Afghan population has been impacted by its most recent wars that began with the Soviet invasion in 1979. Continued unrest has impacted the physical and mental health of many Afghans. For example, in 2010 the Afghan Government estimated that 66% or more of the Afghan population suffered from psychological problems (Banks, Sharpe, Oates, Tarasick, & Wright, 2011).

Turner (2006) reported that mental health problems such as depression, post traumatic stress disorder (PTSD), and anxiety were more prevalent in Afghanistan compared to other countries experiencing war. However, access to treatment for mental health problems was difficult in Afghanistan because of their cultural views surrounding mental illness. As a result of the negative stigma around mental illness, an Afghan who accessed mental health services may have been viewed as "crazy." This served as a deterrent to seeking treatment (Lipson, Omidian, & Paul, 1995; Banks et al., 2011). Additionally, mental health facilities and trained mental

health professionals were sparse in Afghanistan. As a result, the capacity to treat and prevent mental health problems was severely limited (Lopes Cardozo et al., 2005; Banks et al., 2011).

**2.1.2. Afghan women.** Afghan women have been considered one of the most oppressed groups in the world (Brodsky & Faryal, 2006). According to Brodsky (2011), these women have experienced centuries of gender oppression. This gender oppression has only been compounded by the events of the last thirty years. The Taliban restrictions on women from 1996 to 2001 included severe loss of human rights, social confinement, and restricted access to healthcare (Lopes Cardozo et al., 2005; Turner, 2006). Violations of human rights have had a debilitating effect on the health of Afghan women (Amowitz et al., 2003; Krippner & McIntyre, 2003; Turner, 2006; Heath & Zahedi, 2011). For example, results of a survey administered in 1998 indicated very poor mental health among Afghan women: 97% reported major depression; 86% reported significant anxiety; 42% met the diagnostic criteria for PTSD; and 21% reported having suicidal thoughts quite or extremely often (Iacopino et al., 1998). In another study, the mental health of women who lived in Taliban-controlled areas suffered more significantly than those who were not exposed to Taliban regulations. Among those who lived in Taliban-controlled areas, 73-78% and 65% (respectively) experienced major depression and suicidal ideation; among those who did not live in Taliban-controlled areas, 28% and 18% (respectively) experienced major depression and suicidal ideation (Amowitz et al., 2003; Brodsky, 2011).

Although the Taliban regime has ended and women's liberties have improved, Afghan women have continued to struggle with mental and physical health problems. Brodsky (2011) said, "The 2001 Taliban defeat and promises of liberation, democracy, and peace have not lessened the negative mental health impacts on Afghan women" (p. 76). In 2009, Dr. Fatemie, Afghanistan's Minister of Public Health (as reported in Aziz, 2011, p. 230), considered the deteriorated state of women's mental health to be an "epidemic", and placed it second in priority to maternal and child health. According to Turner (2006), "the health status of women in Afghanistan is considered to be one of the poorest in the world. This is reflected by poverty levels, human rights violations and maternal deaths" (p. 757). The main sources of trauma that Turner (2006) identified were motor vehicle accidents and maternal and child health. Afghan women in some parts of the country have also been exposed, sometimes repeatedly, to traumatic events including ongoing war (Amowitz et al., 2003); war horrors such as landmines and bombs (Krippner & McIntyre, 2003); drought; economic stagnation (Lopes Cardozo et al., 2005);

international isolation (Amowitz et al., 2003); poverty (Amowitz et al., 2003; Lopes Cardozo et al., 2005); the loss of family, friends, lifestyle, and property (Lipson & Miller, 1994; Amowitz et al., 2003; Krippner & McIntyre, 2003); and both physical and psychological abuse (Lopes Cardozo et al., 2005; Peterlin, 2009). The health of Afghan women has been an ongoing concern in Afghanistan.

Lopes Cardozo et al. (2005) discovered that there were significant differences between Afghan men and women with regards to their mental health status and ability to function socially: depression was prevalent in 73% of women, and in 59% of men; anxiety was prevalent in 84% of the women, and in 59% of the men; PTSD was prevalent in 48% of the women, and in 32% of the men; and social functioning, a subscale from the SF-36 Health Survey, was 52.00 in women, and 66.63 in men (on a scale of 0-100, higher values correspond with greater ability to function socially). Findings by Turner (2006) and Miller et al. (2006, as reported in Brodsky, 2011) also supported these conclusions. They reported that Afghan women had greater mental health problems than men in areas such as depression, anxiety, and PTSD. Lopes Cardozo et al. (2005) said that this “highlights the negative impact that war, restrictions in freedoms, and socioeconomic hardships have had on the mental health and social functioning of women in Afghanistan.” (p. 285)

In Afghan culture, mental illness has been associated with social stigma. Aziz (2011) expressed that, because of social stigma, psychosomatic expressions of mental illness have become the cultural norm:

Women tend to express their emotions psychosomatically. For example, it is not uncommon for Afghan women to complain about physical ailments for which there are no perceptible medical causes. Due to the lack of mental-health training, medical professionals often misdiagnose and prescribe medications that don't address the actual problems. (p. 237)

## **2.2. Impact of Immigration on Health**

**2.2.1. General.** Studies have identified that immigrants have faced many obstacles in their new country of residence (Lipson, 1991; Krippner & McIntyre, 2003; Carter, 2005; Im et al., 2009). These obstacles may have resulted from an inadequacy in meeting basic needs, and/or they may have resulted from feelings of emotional and psychological distress. Meeting basic

needs has been difficult for immigrants as they have looked for housing and employment, have learned a new language, and have strived to obtain higher levels of education (Lipson, 1991). Some immigrants have also experienced feelings of isolation and culture shock as they have moved from familiar to unfamiliar social, cultural, psychological, and physical settings. Some have believed that their host country and/or their children have not valued their ways of life. This has led to family conflict concerning ways of life and cultural values. Some immigrants have experienced the effects of racism, minority status, poverty, and/or pre-immigration trauma. Some have felt guilty for leaving their home country or for living when others back home were killed (Lipson, 1991; Krippner & McIntyre, 2003; Carter, 2005; Im et al., 2009).

**2.2.2. Afghan refugees and immigrants.** By 1991, 3.4 million Afghan refugees had fled to Pakistan and 2.2 million Afghans were in Iran (Lipson, 1991). At times, these refugees were exposed to very difficult circumstances (Lipson, 1991; Lipson & Miller, 1994). Some who lived as refugees in Pakistan had less access to good medical care than what was available in Afghanistan at the time (Lipson, 1991; Rasekh, Bauer, Manos, Michele, & Iacopino, 1998). In general, the effects of poor health were greater for Afghans living in Pakistan compared to those still living in Afghanistan (Rasekh et al., 1998). Their experiences as refugees may have exacerbated the mental health status of many Afghan immigrant women (Lipson, 1991).

The prevalence of major depression in Afghan refugees has been greater than the prevalence of major depression in other refugee populations in the United States (Amowitz, Heisler, & Iacopino, 2003). Stress has also continued to be a problem for Afghan immigrants as they have dealt with past traumas and losses (Aziz, 1999; Omeri, Lennings, & Raymond, 2006; Aziz, 2011); cultural adjustments related to food, dress codes, and levels of freedom for women and children (Lipson et al., 1995; Aziz, 1999; Aziz, 2011); family conflict over change and acculturation (Omeri et al., 2006); occupational and financial stress in their new host country, including the inability of trained professionals to get a job in the area of their training (Lipson 1991; Lipson et al., 1995; Omeri et al., 2006); language barriers (Lipson, 1991; Omeri et al., 2006); feelings of discrimination (Omeri et al., 2006; Dossa, 2008); concern for the future (Lipson et al., 1995); survivor guilt that they were spared when many loved ones were killed (Lipson, 1991); and concern regarding the on-going trouble in Afghanistan and those they left behind (Lipson et al., 1995; Aziz, 1999; Dossa, 2008; Sartip, 2010; Welsh & Brodsky, 2010; Aziz, 2011). The published research has explored the health of Afghan refugee immigrants



living in Canada (Dossa, 2008), Australia (Omeri et al., 2006), and the United States (Lipson, 1991; Lipson et al., 1995; Aziz, 1999; Sartip, 2010; Welsh & Brodsky, 2010; Aziz, 2011).

A number of studies have explored the physical and social support that Afghans have received after leaving Afghanistan. A study in 2008 showed that Afghan immigrants living in Canada did not feel adequately supported. These immigrants felt isolated from Canadian society due to language barriers, financial circumstances, and racism (Dossa, 2008). Another study in 2010 indicated that, in the United States, Afghan refugee widows did not receive adequate provision for their physical and psychological needs (Sartip, 2010).

In leaving Afghanistan, Afghan immigrants have experienced many losses. Materially, they have lost property, careers, and material goods. Physically they may have lost their health, and they may have experienced hunger, physical injury, and malnutrition. Spiritually, they have lost the support of their religious communities. Relationally, they have lost community support, family members, and friends (Lee, 1997, as reported in Aziz, 1999). The losses of family, culture, property, and status have been the most difficult losses that Afghan women have faced when leaving Afghanistan (Aziz, 1999).

**2.2.2.1. Afghan women.** Suffering has continued for many Afghan immigrant women. Many of these women have faced an on-going struggle with mental and physical health problems (Dossa, 2008). They have also continued to be deeply impacted by what is happening in Afghanistan (Welsh & Brodsky, 2010). In addition to the stress of receiving news from Afghanistan (Welsh & Brodsky, 2010), they have faced difficulties related to learning a new language (Sartip, 2010); finances (Lipson & Miller, 1994; Sartip, 2010); missing home (Lipson, 1991); physical symptoms such as back pain, body aches, and headaches (Lipson, 1991; Dossa, 2008); loss of status; social isolation; and culture conflict (Lipson & Miller, 1994; Aziz, 1999). Factors that have contributed to social isolation include language barriers, financial circumstances, racism, (Dossa, 2008) and cultural values, such as the finding of an appropriate mate (Lipson & Miller, 1994; Aziz, 1999). Culture conflict has been different across genders and generations, but has included questions regarding levels of freedom for women, levels of integration into their host country's culture, and the balance of old and new roles (Lipson & Miller, 1994; Aziz, 1999). Some Afghan immigrant widows of war have faced additional difficulties in forming new identities (Sartip, 2010).

## **2.3. Immigration and Access to Healthcare**

**2.3.1. General.** Studies have identified barriers that immigrant populations have faced when accessing health care. The following barriers were identified: cultural sensitivity, language barriers, difficulty with transportation to services (Lipson, 1991; Carter, 2005), and mistrust of the healthcare professionals (Carter, 2005).

**2.3.2. Afghan immigrants.** Omeri et al. (2006) found that access to health services for Afghan immigrants in Australia was restricted because the services were “culturally incongruent” (p. 34). Afghan immigrants hesitated to access health services for a number of cultural reasons: (a) health promotion strategies were not always culturally appropriate; (b) health services and procedures were not always compatible with Islamic beliefs; and (c) health services did not always support Afghan cultural values surrounding illness and health (e.g., having family support in time of illness).

**2.3.2.1. Afghan women.** In Afghan culture, the family unit is central to life. Afghan women have not considered their lives to be separate from the rest of their family. They “do not separate their needs from those of their husbands and their children.” (Billaud, 2008, p. 371) They have placed others’ needs above their own. “[E]xtended family obligations, especially to parents and older siblings, often supersede other responsibilities, including allegiance to one’s spouse, one’s job, and certainly one’s own needs.” (Lipson & Miller, 1994, p. 174) Because of their family-oriented perspective, many Afghan women have not felt comfortable in programs that have targeted women exclusively as beneficiaries (Billaud, 2008), and they may have been less inclined to access the healthcare system for their personal needs.

Studies have shown that Afghan immigrant women may not have received adequate support for their physical and mental needs. Sartip (2010) reported that the United States health system neglected the psychological and physical needs of Afghan widows. Dossa (2008) concluded that Afghan immigrant women were not adequately supported in their move to Canada because of isolation. According to Aziz (1999), social isolation was likely the hardest factor of immigration, exacerbating psychosomatic symptoms and depression.

## **2.4. Pain and Immigrant Health**

**2.4.1. Concepts and definitions.** Pain is a complex, multi-dimensional experience. The International Association for the Study of Pain (IASP) defined pain as “an unpleasant sensory

and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.” (IASP, 2011) Pain, then, is both sensory and emotional and occurs with or without tissue damage. Furthermore, “pain is always subjective. Each individual learns the application of the word through experiences related to injury early in life.” (IASP, 2011) Previous encounters shape pain experience.

A number of variables influence pain experience. Nociception is noxious sensory input that may lead to the experience of pain (Wall & Melzack, 2006). The central nervous system (CNS) may inhibit or facilitate this nociceptive input (Bradley & McKendree-Smith, 2002). Additionally, pain may originate in the CNS in the absence of nociceptive input. Wall & Melzack (2006) stated that the experience of pain “depends on a host of variables, including the presence of other somatic stimuli and psychological factors such as arousal, attention and expectation. These psychological factors in turn are influenced by contextual cues that establish the significance of the stimulus and help determine appropriate responses to it.” (p. 125)

**2.4.2. Pain in immigrants. 2.4.2.1. General immigrants.** A number of factors correlated with pain experience in immigrant populations. Higher levels of more disabling pain seemed to correlate with socioeconomic factors such as financial strain and occupational difficulties (Lofvander, Engstrom, & Nafezi, 2004; Soares, Sundin, & Jablonska, 2004; Stanaway et al., 2011); mental health problems including exposure to traumatic experiences, anxiety, stress, or depression (Soares & Grossi, 1999; Lofvander et al., 2004; Soares et al., 2004); segregation from other people (Lofvander et al., 2004); and a history of torture (Olsen, Montgomery, Bojholm, & Foldspan, 2007). Some of these factors may be identified among Afghan immigrants, especially the women; Afghan women have experienced more mental health problems compared to Afghan men (Amowitz et al., 2003; Lofvander et al., 2004; Sartip, 2010).

Immigrant groups across all ethnicities have had higher levels of more constant and disabling pain compared to the average levels of pain identified in host countries (Lofvander, 1999; Soares & Grossi, 1999; Lofvander et al., 2004; Soares et al., 2004; Im et al., 2009; Stanaway et al., 2011). Furthermore, a secondary source to publications that are not available in English (Soares & Grossi, 1999) described that: (a) seven studies carried out in Sweden had found that immigrants have a higher risk of developing severe and prolonged illness, emotional distress, and functional impairments (especially musculoskeletal pain disorders), compared to

locals; and (b) similar results had been observed in immigrant groups from Germany and Norway.

Immigrant populations may have different views on treatment of pain. According to Green et al. (2003), African Americans and Hispanic cancer patients tended to rely more on alternative pain treatments compared to analgesics alone when they experienced severe pain. Lofvander et al. (2004) reported that Swedish immigrants on long-term sick leave, aged 20 to 45, spent a lot of time resting because of pain, and preferred passive treatment for their pain (e.g., rest or massage) compared to active treatment such as exercise. Lofvander et al. (2004) explained that, although physical exercise and cognitive support are perhaps the most effective treatments available for benign chronic low back pain, treatment strategies needed to align with immigrant populations' belief systems, knowledge, and cultural traditions.

Lofvander (1999) discovered that patients who focused on the sensation of pain, rather than on the meaning or cause of their pain, fared better overall. Additionally, the patients who focused on pain sensation tended to attribute their pain to fate. These patients were more accepting of their pain and included Muslim patients who said *Inshallah* or "If Allah wants" when referring to the future of their health. More positive pain outcomes were evident in patients with this belief system (Lofvander, 1999).

**2.4.2.2. Afghan women.** Aziz (1999; 2011) described a relationship that has existed between physical pain and mental health among Afghan women. She described this relationship in terms of cultural appropriateness, stating that mental illness may not have been expressed due to social stigma. She said: "Physical pain is more acceptable and less stigmatizing than the stigma associated with mental illness." (Aziz, 1999, p. 167) Therefore, mental illnesses such as PTSD and major depression have been expressed psychosomatically, and may have included diffuse pains such as heart pain and severe headaches (Aziz, 1999; Aziz, 2011).

**2.4.2.3. Pain management disparities.** According to the literature, there have been disparities in the assessment and treatment of pain in ethnic minorities. This has led to under-treatment of pain for ethnic minorities across multiple pain conditions (Green et al., 2003; Im et al., 2009; Stanaway et al., 2011). In Green et al.'s literature review, these disparities crossed all settings that were reviewed (i.e., post-op and emergency room settings) and all types of pain (i.e. acute, cancer, chronic nonmalignant, and experimental pain). Reasons for the disparities were

complex, and were attributed to the patient, the healthcare professional, and the healthcare system.

The patients' contribution to disparities in the assessment and treatment of pain involved their communication with the healthcare professional (including level of language proficiency), attitudes and beliefs, and knowledge of health practices and available resources. Language proficiency was recognized as the most likely commonly identified barrier to care. Beliefs and concerns that may have affected care included the beliefs that: a) rest is the best treatment for pain (Lofvander, 1999); b) exercise should be avoided as treatment for pain (Lofvander et al., 2004); c) pain is inevitable and must be accepted; and d) work is the main etiological factor causing pain (Lofvander, 1999). Also important were concerns about using opioids, such as addiction, tolerance, and side effects (Green et al., 2003; Im et al., 2009). Lack of knowledge regarding what help was available may have also inhibited patients from seeking optimal treatment for their pain (Im, Ho, Brown, & Chee, 2009). Ekeus, Cnattingius, and Hjern (2010) pointed out that some immigrant women expected the delivery of care in their host country to be similar to what they would have received in their country of birth.

Ekeus et al. (2010), in a study about the use of epidural analgesia (EDA) by immigrant women during labor, demonstrated how patient characteristics might influence pain management. The purpose of the study was to examine whether the use of EDA by immigrant women experiencing labor was different than the use of EDA by Swedish locals. Results showed that having a partner who spoke Swedish fluently led to higher use of EDA, as did having a higher social position. Ekeus et al. (2010) concluded that having language proficiency is important for communicating one's needs effectively, which may lead to better pain management. Ekeus et al. also reported that having a higher social position may have led to greater language proficiency, higher levels of education, and greater knowledge of what is available for pain relief during labor. The authors suggested that these factors might have led to greater use of EDA in some immigrants. However, a limitation of the study was the assumption that any woman who is knowledgeable in pain relief during labor would choose EDA. Furthermore, the authors did not consider cultural factors that may influence a decision to use or refrain from using EDA.

Healthcare professionals and healthcare system structures have also had significant roles in the assessment and treatment of pain in immigrant populations. The decisions made by

healthcare professionals concerning assessment and treatment techniques (Green et al., 2003), and their ability to appropriately assess pain in patients who speak different languages and/or come from different cultures (Im et al., 2009), have affected management of pain. In the structure of healthcare systems, Green et al. (2003) and Im et al. (2003) promoted making healthcare more geographically accessible (e.g., having clinics that are within walking distance for those who are unable to travel distances), culturally accessible (e.g., having culturally sensitive standards of care), and financially accessible (e.g., for buying prescriptions). Im et al. (2009) also indicated that scales developed for “Whites” don’t necessarily translate to other ethnicities (p. 366-367). Outcome measures need to be tested and proven valid and reliable for the populations for which they are being used.

To be effective, healthcare professionals should consider how previous experiences influence immigrant health. According to Krippner & McIntyre (2003, p. 270), “Psychological and emotional injuries may be the most enduring effects of war...” but healthcare professionals have often overlooked or minimized these effects. Additionally, Carter (2005) stated that the reasons immigrants left their home country, and the level of control they had over circumstances during immigration, has been an important consideration in mental health. If the level of control over circumstances was low, immigrants may have fared worse than if the level of control over circumstances was high. This was also demonstrated in Soares & Grossi’s (1999) study: immigrants in Sweden felt lack of control and relied on passive coping strategies. The immigrants reported less control over their work environment and less control over their pain compared to the local Swedes. To cope with their pain, they used pain medications and pain avoidance more often than the local Swedes. These passive coping strategies corresponded with an external locus of control, and these immigrants experienced a more significant impact of pain on their lives compared to local Swedes.

## **2.5. Summary**

From the literature, it is clear that immigrants have faced many challenges in their host countries. Immigrants have had higher levels of more disabling pain compared to average levels of pain identified in their host countries. Moreover, immigrants have experienced disparities in the assessment and treatment of their pain. Their access to healthcare has often been restricted because of cultural differences.

As immigrants in Canada, Afghan women may also experience higher levels of disabling pain, and greater disparities in assessing and treating their pain, compared to national norms. Afghan women, in particular, have experienced health deficits as a result of war in Afghanistan. The suffering that Afghan women have experienced has continued after leaving Afghanistan. As immigrants, Afghan women have continued to struggle with mental and physical health problems. The literature suggests that they may not receive adequate support for their physical and mental needs in Canada, and that they may be less inclined to access the healthcare system as a result of cultural differences.

Although the literature addressed mental health problems among Afghan women, there is a gap in the literature regarding chronic pain in Afghan women. Evidence from the literature suggests that chronic pain might be a problem for Afghan immigrant women. Exploratory research, using qualitative methods, is needed to learn about Afghan immigrant women's experiences and perspectives with regards to chronic pain and its management. Therefore, this study explored the experience and management of chronic pain from the perspectives of Afghan immigrant women, using primarily qualitative methods to gain an "insider" perspective. Potential barriers to healthcare access have also been explored.

## **Methodology**

### **3.1. Research Objectives & Questions**

The literature has indicated that Afghan immigrant women suffer from poor physical and mental health; consequently, chronic pain might be a problem for Afghan immigrant women. Therefore, the purposes of this study were: (a) to describe the physical and mental health status of Afghan immigrant women in one Canadian city; (b) to construct an Afghan cultural model of pain (experience and management) using interview data and available literature; (c) to explore the experience of chronic pain and its management among Afghan immigrant women, both culturally and individually; and (d) to identify potential barriers to chronic pain management for both Afghan immigrant women and their health care providers. Research questions for the quantitative portion of this study were as follows:

1. To what extent does the mental and physical health of each individual Afghan immigrant woman participant compare to national norms?
2. What are the demographic characteristics of participants in Part 1 (includes prevalence of chronic pain, age, pre-immigration refugee status, language preferences, and levels of education)?

Research questions for the qualitative portion of this study were as follows:

1. What concepts and relationships derived from first- and second- hand informants and the literature contribute to a cultural model that describes how Afghan women experience and manage their pain?
2. What are the pain experiences of Afghan immigrant women, and how do personal and cultural perspectives impact their pain experiences?
3. What pain management strategies do Afghan immigrant women use, and how do personal and cultural perspectives impact their management strategies?
4. What barriers exist in the experience and management of chronic pain for Afghan immigrant women?



**3.1.1. Research questions – planned.** Planned research questions for the quantitative portion (Part 1) of this study were:

1. How do mental and physical health of Afghan immigrant women in one Canadian city compare to national norms?
2. What is the prevalence of chronic pain among Afghan immigrant women in one Canadian city compared to national norms?

Due to unexpected recruitment difficulties, the two research questions for Part 1 were not addressed in this study. The research questions were reframed to provide the basis for a more modest descriptive project. In Chapter 7, possible reasons for recruitment difficulties are discussed.

## **3.2. Ethical Considerations**

The Research Ethics Board at the University of Saskatchewan approved this study in January of 2012, with five amendments approved in the following six months. This study was considered greater than minimal risk because Afghan immigrant women are a potentially vulnerable population. Afghan women have experienced high rates of depression, anxiety, and suicidal ideation in Afghanistan, although the prevalence of these conditions was not known among the immigrant population being studied. Consequently, I discussed available counseling support with Afghan women participants and gave them contact information for a local counselor. Because they may have been uncomfortable seeking outside counseling support (S. Niazi, personal communication, March 2012), participants were encouraged to seek support where they felt most comfortable. The local counselor was presented as one option, and participants were reminded that they could find someone of their choice to talk to.

To protect their privacy, women involved in the qualitative portion of this study have been identified using pseudonyms. Participants chose their own pseudonym or, if they preferred, were assigned a pseudonym. The key that links pseudonyms to names and contact information has been stored on a computer. The computer account and file containing the key both require passwords for access. All other electronic data has also been stored on a computer that requires a

password for access. Any non-digital data has been stored and locked in an office in the School of Physical Therapy at the University of Saskatchewan.

### **3.3. Study Design - Mixed Methods**

A mixed methods approach was used for this study. According to Jackson & Gillis (2003), “qualitative and quantitative research should be seen as complementary to one another” (p. 137). In the health sciences, mixed method study designs have become increasingly popular. One of the benefits of the mixed methods study design is its ability to carry out participant-based research. Researchers are able to integrate the individual perspectives and lifestyle factors of their participants when utilizing both qualitative and quantitative methods (Tashakkori & Teddlie, 2003; Townsend, Cox, & Li, 2010).

This study began with the quantitative component “in order to establish a sample of respondents and to establish the broad contours of the field.” (Silverman, 2008, p. 48) Then, the qualitative component explored “in depth at a key issue using some of the earlier sample.” (Silverman, 2008, p. 48) Additionally, standardized questionnaires were used in the qualitative interview in order “to locate the results in a broader context.” (Silverman, 2008, p. 48) This can be symbolized as: quant → (QUAL+ quant). The qualitative component was the primary focus of this study, with quantitative data used to collect health information, identify participants with chronic pain, and supplement the qualitative data (Tashakkori & Teddlie, 2003, p. 197-198, 214). As the primary focus, the qualitative component emphasized the importance of the patient perspective (Thorne, 2008, p. 245).

The study had two parts. In Part 1, questionnaires were used to describe the health status of the community of Afghan immigrant women. Part 1 was also used to identify participants who were eligible to join Part 2. In Part 2, semi-structured interviews were the primary source of data; interviews were supplemented by three short quantitative questionnaires. Part 2 was used to explore the experience of chronic pain and its management, both culturally and individually; and to identify potential barriers to chronic pain management for both Afghan immigrant women and their health care providers.

**3.3.1. Part 1 – description of health status.** Part 1 was used to evaluate the physical and mental health statuses of Afghan immigrant women using a health status measure called the

Short Form 36 Health Survey (SF-36). (The SF-36v2 Health Survey may be reviewed at the following URL, published with permission from OptumInsight Life Sciences, Inc. [See Appendix A]: [http://www.qualitymetric.com/demos/TP\\_Launch.aspx?SID=100](http://www.qualitymetric.com/demos/TP_Launch.aspx?SID=100)).

Demographic information was also collected in Part 1, and participants were screened for chronic pain (see Appendixes B and C).

**3.3.1.1. Inclusion criteria – part 1.** Afghan women (born in Afghanistan), aged 17 years or older, were able to join this study. The women were required to have spent at least part of their lives in Afghanistan. They may or not have been a refugee elsewhere (e.g., Pakistan) before arriving in Canada. Fluency in the English language was not a requirement; women could participate using either English or Farsi.

**3.3.1.1.1. Inclusion criteria – part 1 planned.** In the planned inclusion criteria, Afghan women aged 18 years or older were able to join this study. An Afghan woman aged 17 years old, who assisted her mother in completing Part 1, also participated in Part 1. She was included because of her interest in the study and because she was eligible based on all inclusion criteria except age.

**3.3.1.2. Recruitment – part 1.** The snowball sampling technique was used in an attempt to recruit about 50 women for Part 1. Participants were encouraged to recruit other members of their community who had not yet joined the study. I was also in regular contact with two Afghan women who agreed to help spread the word about this study (M. & S. Niazi, personal communication, December 15, 2011).

To supplement personal contact, other recruitment strategies were utilized. Posters were displayed at the offices of the local non-profit organizations that work with immigrant populations. Pamphlets were given to personal contacts that work with two non-profit organizations in the area. Contacts were asked to distribute the pamphlets to any Afghan women they knew. I also attended two Afghan social gatherings. At the first event, I shared briefly about the research and distributed pamphlets to about 30 to 40 women. At the second gathering, I distributed research packages for Part 1 to 5 Afghan women interested in the study.

With poor response to the *a priori* recruitment plan, an amendment was submitted to and approved by the Research Ethics Board (REB) in July of 2012, which allowed me to contact women using a telephone list provided by a member of the Afghan community. Even with the

addition of this telephone list, recruitment was only minimally successful. Despite the intensive and varied efforts to recruit participants for Part 1, recruitment was far lower than planned.

**3.3.1.3. Procedures – part 1.** Upon initial telephone or email contact with potential participants, I discussed the procedures and expectations of Part 1. Women who were interested in participating received all written materials at a time and location of their convenience. They were encouraged to read the consent form thoroughly before signing it and completing all other forms. Participants were also encouraged to ask any other questions that they had during the completion of written forms by contacting me by telephone. They could complete forms on their own in either English or Farsi. Those participants who were unable to read or write in English or Farsi, or who were not comfortable filling out forms, could complete all forms with the help of a family member or with me. In an attempt to increase participation during the summer of 2012, I proactively offered to assist participants with completing written forms at a time and place of their convenience, rather than waiting for requests for help. Participation increased slightly, although recruitment continued to be a challenge.

**3.3.1.4. Instrumentation – part 1.** Three forms, in addition to consent forms, were included in Part 1. These forms included the demographic questions, pain questions, and the SF-36 (See Appendix B and C). The SF-36 was available in both English and Farsi. Demographic questions, pain questions, and consent forms were translated from English into Afghan Farsi, making these materials available to all participants in both English and Farsi. Participants were encouraged to use the translation that they felt most comfortable with.

The SF-36 is a health status measure that categorizes health into physical and mental health domains. This tool has been found to be valid and reliable in many different cultural and language settings. It has been translated into Iranian Farsi, and studies have been completed to confirm its validity and reliability in Iranian Farsi (Montazeri, Goshtasebi, Vahdaninia, & Gandek, 2005; Koocheck et al., 2007; Mohammadpour & Yousefi, 2008). The Iranian version of the SF-36 was developed at a time when political differences prevented the United States from communicating with Iran. Therefore, the Iranian version has not been available through QualityMetric, where most other translations of the SF-36 are accessed. In order to use this version of the SF-36, I communicated directly with one of the authors of the Iranian translation, A. Montazeri, who works at the Iranian Institute for Health Sciences Research in Teheran.

Because Iranian Farsi is similar to Afghan Farsi (M. Niazi, personal communication, November 7, 2011), participants who did not speak English well were able to complete the Iranian translation of the SF-36 without much difficulty. Participants who were able to communicate in both English and Farsi were also asked to complete the SF-36 Health Survey in both languages, with the original intent to analyze the interchangeability of using English and Farsi translations. Those participants who preferred to complete the SF-36 in one language only, either English or Farsi, were encouraged to do so.

**3.3.1.5. Data analysis – part 1.** In this study, individual SF-36 scores were compared to national norms. The SF-36 uses a scale from 0 to 100 with higher scores indicating better health status. The SF-36 was used in this study to determine overall health status for each participant; to differentiate between physical and mental health components for each participant; and to assess the eight SF-36 health subscales for each participant. These subscales include: physical functioning; role-physical, or “role limitations due to physical problems”; bodily pain; general health; vitality; social functioning; role-emotional, or “role limitations due to emotional problems”; and mental health, or “perceived mental health” (Koocheck, Montazeri, Johansson, & Sundquist, 2007, p. 61).

Calculating SF-36 scores was a multi-step process. First, I used the Health Outcomes Scoring Software 4.5 (© 2011, QualityMetric Incorporated) to score the English questionnaires, and Microsoft Excel and the SF-36 Health Survey Manual (Ware, Snow, Kosinski, & Gandek, 1993) to score the Farsi questionnaires. The Farsi questionnaires were scored manually because these questionnaires are SF-36v2, a version that is not compatible with Health Outcomes Scoring Software 4.5. After determining the eight subscale values using these methods, I calculated the physical component summary (PCS), mental component summary (MCS), and norm-based scores (NBS) for all participants using Canadian norms. To do this, I used the NBS Calculator, an online calculator developed by SF-36.org (NBS Calculator, accessed January 24, 2013). Using the eight subscale values for each participant, the online calculator produced NBS using normative data from the general Canadian population (n=9423, no date) and figures that compared each participant’s values to national norms (see Table 1 and *Figure 1*).

**3.3.1.5.1. Data analysis – part 1 planned.** Planned analyses for Part 1 were: (a) to compare the Afghan community’s SF-36 values to national SF-36 norm values; (b) to calculate the correlation between the English and Farsi translations of the SF-36 for participants who

completed the SF-36 in both languages, using Spearman's non-parametric rank order correlation coefficient (Vincent, 2005; Johnson & Bhattacharyya, 2001); and (c) to estimate the prevalence of chronic pain among Afghan immigrant women and compare the estimates to national norms. These analyses were not completed because participation in Part 1 was too low.

**3.3.2. Part 2 – interviews.** The interviews in Part 2 were semi-structured one-on-one interviews. These interviews were audio-recorded and transcribed. Additionally, participants with chronic pain were asked to complete three quantitative pain questionnaires: (1) the Faces Pain Scale - Revised; (2) the Short Form McGill Pain Questionnaire; and (3) the Body Diagram. These questionnaires were integrated into the interview guide Segment 3: Symptomology of Pain (see Appendix D).

**3.3.2.1. Inclusion criteria – part 2.** Afghan women with chronic pain (pain lasting 6 months or longer), whether continuous or intermittent, were eligible to participate in the qualitative component of this research. For inclusion in this component of the research, participants had to be Afghan immigrant women living in a specific Canadian city, aged 18 years or older, who had spent at least part of their lives in Afghanistan, and who considered Afghan culture to be important to their formation. Refugee status elsewhere (e.g., Pakistan) before arriving in Canada was not an exclusion.

Due to the difficulties of recruitment in Part 1, we (the student and supervisory committee) reconsidered possible sources of data related to the experience and management of chronic pain in Afghan immigrant women. The inclusion criteria were expanded to include second-hand experience of chronic pain in Afghan immigrant women and/or experience working with Afghan immigrant women in clinical settings. The Research Ethics Board (REB) approved the expanded inclusion criteria in November of 2012.

**3.3.2.2. Recruitment – part 2.** Interpretive description methodology recommends recruiting and selecting participants purposefully in an attempt to reveal elements of their pain and its management that are shared by others (Thorne et al., 1997). This purposive sampling is a strategically important component of many types of qualitative research (Jackson & Gillis, 2003). Planned purposive sampling for Part 2 was dependent on participants' first hand experiences with chronic pain, and planned recruitment for Part 2 was dependent on participation in Part 1.

An amendment, approved by the REB in November of 2012, allowed me to recruit participants into Part 2 without participation in Part 1. The amendment was made because Part 2 was the primary focus of this study and because participation in Part 1 was low. At the time of amendment approval, recruitment for Part 1 ended and recruitment for Part 2 continued through the community telephone list (see Recruitment – Part 1). Recruitment in this study was also expanded to include second-hand experience of chronic pain and/or experience working with Afghan immigrant women in clinical settings (see Inclusion Criteria – Part 2). The family member of a woman experiencing chronic pain was recruited using the same recruitment methods used with other Afghan immigrant women. A healthcare professional was recruited via email, based on experience working with Afghan immigrant women in clinical settings.

**3.3.2.3. Procedures – part 2.** If prospective participants were interested in the interviews, a consent form was delivered to them for review. Potential participants were then contacted by telephone or email to discuss procedures and answer questions before the consent form was signed. For those women who were still interested in becoming participants after this, two interviews were scheduled within a period of no more than two weeks (when possible). Completing interviews in this time period was done to ensure that participants remembered information that was covered in the first interview as they completed the second interview. When possible, interviews took place at an office on the university campus. A “Do Not Disturb, Interview in Progress” sign was posted on the door during interviews. This was done to ensure that interviews were completed with minimal distractions or interruptions.

To increase participation as the study progressed, interviews were also completed in participants’ homes. Meeting together in participants’ homes greatly increased the number of distractions and interruptions that occurred during interviews; at times, this had a negative impact on the quality of the collected data. However, completing interviews in their homes allowed 3 of 5 primary informants to participate in this study. These changes were necessary to accommodate Afghan immigrant women’s home responsibilities, to recruit participants that spanned multiple generations and represented contrasting perspectives, and to recruit an adequate number of participants.

All interviews were audio-recorded and transcribed using the basic transcription symbols on page xx. Reflective comments, impressions, or any behaviors or gestures that stood out

during the interview were recorded within a day (when possible). Whenever possible, the first interview was transcribed before engaging with participants in their second interview.

The second interview took place at the same location as the first interview, whether in the campus office or in participants' homes. The topics that were covered in the second interview were determined based on content from the first interview that needed further clarification, or based on information that the participant felt she missed during the first interview but wanted to discuss during the second interview. Like the first interview, the second interview took between one and two hours.

*3.3.2.3.1. Practice interviews.* I conducted practice interviews using the interview guide with non-participants. This provided an opportunity to test audio-recording software, develop interviewing skills, and test and refine the interview guide. It also provided an opportunity to reflect on the involvement that would be required for conducting interviews in Farsi with translation. Through the interview practice, it was concluded that conducting interviews in Farsi would require more involvement than time permitted for this Masters Thesis. In collaboration with the Research Advisory Committee, it was decided that interviews would be completed in English only.

*3.3.2.4. Instrumentation – part 2.* The main instruments used in Part 2 were Atlas.ti 7.6 software, for data analysis, and the interview guide (see Appendix D). The interview guide was carefully constructed, and then tested using practice interviews. Three quantitative pain questionnaires were also incorporated into the interview guide and completed by participants who had chronic pain.

The format of interviews included both structured and open-ended questions. The open-ended questions required more thought and consideration from participants. These questions were used to encourage greater depth in the findings (Silverman, 2008, p. 114). From a cultural perspective, open-ended questions may also be more appropriate with this population. Open-ended questions promote a more conversational interview style. According to Amina Kator (2011), interviewing people through conversation is “in keeping with ‘the Afghan way’” (p. 357).

The interviews, which consisted of five segments (Segment 1: Cultural Model of Pain; Segment 2: Origin of Pain; Segment 3: Symptomology of Pain; Segment 4: Management of Pain; and Segment 5: Last Remarks), held up well during the interviews. Only the first segment of the



interview posed questions that specifically targeted cultural views on pain, although the cultural model of pain may have influenced all remaining interview segments. Each of the remaining four interview segments explored personal experience of pain. They are considered, in Chapter 5, as individual experiences within the framework of the cultural model of pain.

Three quantitative questionnaires were completed during the interview segment covering symptomology of pain: the Faces Pain Scale – Revised (FPS-R); the Short-Form McGill Pain Questionnaire, available in both English (SF-MPQ) and Iranian Farsi (I-SF-MPQ); and a Body Diagram. These questionnaires were used to increase understanding of each participant's personal experience of pain. Often, completing these forms prompted participants to spontaneously reveal additional details of their pain experience.

The Faces Pain Scale – Revised (FPS-R) is a pain intensity scale that was originally designed for pediatric populations. When using the FPS-R, participants are asked to point to the one face (of six) that corresponds with their current pain experience. Because it is simple to administer, the FPS-R has also been administered to adult populations who have communication difficulties, including cross-cultural language communication difficulties. Li, Liu, and Herr (2007) found good reliability and validity in using the FPS-R with Chinese adult patients experiencing post-operative pain in an American hospital. They also found that nearly half of participants preferred the FPS-R to other pain intensity scales.

The Short-Form McGill Pain Questionnaire (SF-MPQ) includes three main components: the Pain Rating Index (PRI), Present Pain Intensity (PPI), and Evaluative Overall Intensity (EOI) (see Appendix E). The PRI is the main component, and uses 4-point scales to describe experience of pain. Within the PRI, experience of pain is categorized into eleven sensory and four affective descriptors of pain. The SF-MPQ was designed and tested by Melzack (1987) as a useful alternative to the longer McGill Pain Questionnaire (MPQ). He found that the SF-MPQ had sufficient correlations and sensitivity when compared to the MPQ. Since that time, the SF-MPQ has been widely used, and has been translated into Iranian Farsi (I-SF-MPQ). Adelmanesh et al. (2011) found the I-SF-MPQ both reliable and sensitive in assessing pain changes over time for Persian chronic pain patients.

The Body Diagram is used to represent pain distribution, and is sometimes used to analyze change in pain distribution over time. For this study, participants were asked to represent their pain on the body diagram using colored pencils. Participants were encouraged to

use as many colors as they wished. Although pain distribution was the main function of the body diagram in this study, some participants used colored pencils to represent differences in pain intensity across the body or differences in pain intensity over time. As participants filled the body diagram, they often shared attributes of their pain experience that had not yet been discussed.

The interview guide was modified for the interviews with two secondary informants (the family member and healthcare professional). The family member was asked questions from Segment 1 (Cultural Model of Pain) of the original interview guide, and the healthcare professional was not asked any questions from the original interview guide (see Instrumentation - Part 2). Both informants were asked questions relating to the cultural model of pain (experience and management). Other questions related more specifically to barriers in healthcare access and pain management for Afghan immigrant women.

**3.3.2.5. Data analysis - part 2.** 3.3.2.5.1. *Interpretive description methodology.* This study uses interpretive description methodology. Interpretive description is a qualitative inquiry approach that was established in 1997 and is most suited to research questions that originate from the applied clinical fields (Sandelowski, 2000; Thorne, 2008; Thorne et al., 2009). Rather than description alone, interpretive description explores the meanings and explanations that are within the descriptions with an aim to answer questions that are relevant to the clinical discipline of interest (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). The ultimate purpose of interpretive description methodology is not to theorize, but rather to illuminate insight (Thorne, 2008, p. 169).

Research inquiry that is conducted using interpretive description methodology will, most often, result in a conceptual description or thematic summary (Thorne, 2008). It should also build on a scientific basis or some level of existing knowledge (Thorne et al., 1997; Thorne et al., 2004). In this way, interpretive description is unlike the traditional phenomenological approach, which attempts to explore a phenomenon without consideration of existing knowledge or ideas (Thorne et al., 1997).

According to Braun & Clarke (2006), thematic analysis is a “theoretically flexible approach to analyzing qualitative data” (p. 77). Thematic analysis involves interpreting the data by taking an active role in engaging with it. The process includes six phases: (1) becoming

familiar with the data, (2) using initial codes, (3) looking for themes, (4) reviewing these themes, (5) refining the themes, and (6) producing the report (Braun & Clarke, 2006, p. 87).

In this study, I loosely followed the six phases outlined by Braun & Clarke (2006). First, I familiarized myself with the data by transcribing each interview. (Braun & Clarke, 2006) I transcribed each interview within a week of meeting with the participant. Any comments or questions that came up during this thorough review of the material were written down. After the transcription was complete, all the collected data was entered into Atlas.ti software for the rest of the analytical processes. Here, I used Crabtree & Miller's (1999) coding strategy by starting with broad coding categories followed by more detailed codes and interpretation. As I reviewed the material, I looked for themes. Re-coding and re-organizing of themes happened iteratively as new interviews were added and conceptual patterns developed (Rubin & Rubin, 2005; Oliffe et al., 2007; Thorne et al., 2009). Although coding was used to organize the data, the interpretations that emerged were the product of many hours of thought and intellectual inquiry (Thorne et al., 2004, p. 7). Data from previous interviews were used to steer questions and topics in following interviews whenever possible (Rubin & Rubin, 2005). For example, interviews with secondary informants occurred in later stages of the data collection and analysis, and included questions and topics that had emerged from previous interviews with primary informants. However, using data from previous interviews to steer topics in following interviews was not always possible because of communication difficulties (see Chapter 7, Communication Difficulties).

In addition to thematic analysis, conceptual mapping was used to analyze this study's data. Conceptual maps are visual illustrations of the relationships that exist between concepts. A conceptual map consists of four basic elements: concepts, relationships, statements, and maps. A concept consists of one idea. A relationship links concepts together, and includes the directionality of the relationship, type of relationship, and strength of relationship. A statement brings two concepts together and states the relationship that exists between them. A map is a network that is created from multiple statements (Carley & Palmquist, 1992).

In this study, I used conceptual mapping to bring insight to the relationships that existed among codes and themes. To do this, I used the "Networks" tool available in Atlas.ti. Forming conceptual maps gave me an opportunity to explore the potential causal relationships that existed among codes and themes. It also allowed me to review the codes and themes more closely, to

clarify them, and to emphasize the most important and relevant ones. Conceptual mapping was an important analytical component of this study (see Appendix F).

3.3.2.5.2. *Afghan women cultural model of pain.* An Afghan women cultural model of pain (experience and management) was constructed as part of the analysis in Part 2. Cultural models are “important cultural assumptions and meanings that are available in particular contexts” (Fryberg & Markus, 2007, p. 215). These cultural models are presupposed and taken for granted by those who share them. They are “widely shared (although not necessarily to the exclusion of other alternative models) by the members of a society and that play an enormous role in their understanding of that world and their behavior in it” (Holland & Quinn, 1987, p. 4). Cultural models represent the influence of culture on a community’s cognition, reasoning, and behavior (Holland & Quinn, 1987; D’Andrade, 1989; Fryberg & Markus, 2007).

In this study, a cultural model of pain was constructed to describe how Afghan immigrant women view pain from a cultural perspective. It includes the meaning and expression(s) that their community attributes to painful experiences, and the way that their family and community deal with it. This conceptual model is presented in Chapter 5; it is constructed from interviews with participants and relevant literature (see Tables 2 and 3). Segment 1 of the Interview Guide (see Appendix D) asked specific questions about participants’ cultural model of pain. Literature was searched using the following medical subject heading terms in Medline (1946-2013) and AMED (1985-2013) databases, and key words in the CINAHL database, yielding limited results: *pain; Asia; Asia, Western; culture; cross-cultural comparison; cultural characteristics; cultural diversity; ethnology; and anthropology, medical*. The research advisory committee provided additional references. Near the end of data analysis, two *encultured informants* also reviewed and approved the constructed cultural model of pain for Afghan immigrant women. Encultured informants are “individuals who know the culture well and take it as their responsibility to explain what it means” (Spradley, 1979, p. 47, as cited in Rubin & Rubin, 2005, p. 66).

3.3.2.5.3. *Questionnaires.* Results from the symptomology segment of the interview were viewed within the context of each participant’s interview results. That is, the SF-MPQ, body diagram, and FPS-R were used to enhance understanding of each participant’s experience and management of pain. For the SF-MPQ, calculating the Sensory Pain Rating Index (S-PRI), Affective PRI (A-PRI) and Total PRI (T-PRI) required simple addition. The sum of the sensory descriptors (S-PRI) and the sum of the affective descriptors (A-PRI) together are called the T-

PRI ( $S\text{-PRI} + A\text{-PRI} = T\text{-PRI}$ ). Higher PRI values correspond with more severe pain. Likewise, higher PPI values correspond with more severe pain intensity. The PPI comprises a visual analogue scale (VAS), where present pain intensity is determined by measuring the length of the mark (in cms) along the line from *no pain* to *worst possible pain*, divided by the whole length of the line (in cms).

## **Chapter 4**

### **Quantitative Results – Part 1**

In this section, I use the data to describe the sample and to compare individual SF-36 scores to national norms. No inferential statistics are used.

#### **4.1. Demographics**

Many Afghan immigrants from this study's recruitment population lived as refugees in other countries before coming to Canada (M. Niazi, personal communication, November 7, 2011). Eleven women participated in Part 1. Of those women, five (45%) had experienced chronic pain lasting 6 months or longer. They were between 17 and 65 years of age (median = 37). Nine women left Afghanistan between the years 1996 and 1998. Eight women had lived as refugees in Iran (2), Pakistan (2), Russia (3), or Syria (1) before moving to Canada. When speaking, 5 women preferred to speak English, 4 preferred to speak Farsi, and 2 women were able to speak more than one language. When reading, 4 women preferred to read English, 4 preferred to read Farsi, and 2 were able to read more than one language. Levels of education ranged from 2 years to 19 years (median = 15).

#### **4.2. SF-36 Results**

Although 11 women participated in Part 1, 2 participants were unable to read the English or Farsi forms well enough to complete an SF-36 Health Survey on their own. I attempted to administer the SF-36 orally with them, but they had difficulty responding to the items in the expected manner. They consistently responded by sharing stories and experiences. SF-36 data from these two women are not included in the results because there were concerns about the accuracy of their responses to SF-36 questions.

Table 1 shows the SF-36 results for the remaining 9 participants. The norm-based scores indicate that a score of 50 represents the mean score for Canadians in that category. Participants 2, 3, 4, 7, and 10 had physical component summary (PCS) and mental component summary (MCS) scores that were similar to Canadian averages (scores close to 50). Most participants had

higher physical health scores compared to mental health scores, indicating better physical health compared to mental health.

Participants 1, 3, and 5 had chronic pain (see Table 1 and *Figure 1*). The norm-based scores (NBS) of Participant 3 were similar to average Canadian values (NBS of 50) for both the PCS and the MCS. Because Participant 3 had chronic pain, the fact that her SF-36 NBS were close to Canadian average scores suggest that the SF-36 may not be a good indicator of chronic pain among Afghan immigrant women in Canada (see *Figure 1c* and *1d*). However, more research using larger sample sizes is needed to determine the correlation between SF-36 scores and chronic pain among Afghan immigrant women in Canada.

Table 1.

SF-36 Health Survey Results in English and Farsi Translations, by Physical and Mental Health Subscales, with Norm Based Scores<sup>a</sup>

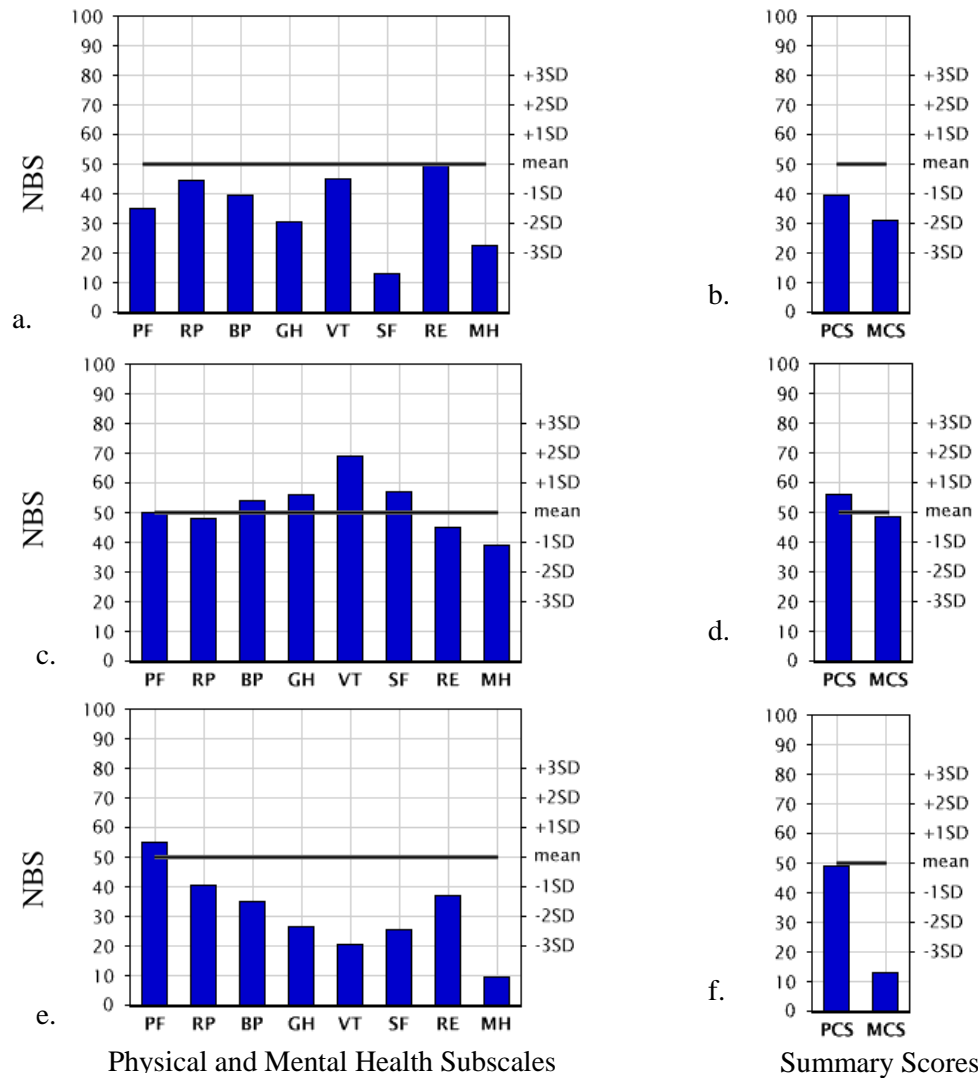
Participant # / Language(s) <sup>b</sup>	Physical Health Subscales					Mental Health Subscales				
	PF	RP	BP	GH	PCS	VT	SF	RE	MH	MCS
1 /										
Farsi	34.6	48.5	39.3	30.2	39.9	44.0	12.8	55.0	22.2	32.4
English	34.6	44.1	39.3	30.2	39.4	44.7	12.8	49.8	22.2	30.8
2 /										
Farsi	57.1	55.4	53.7	55.6	60.0	60.7	44.3	34.0	54.2	43.4
English	57.1	55.4	53.7	55.6	58.2	58.7	44.3	49.8	48.4	46.9
3 /										
Farsi	49.6	47.9	53.7	55.6	55.7	69.0	57.0	44.5	38.6	48.3
4 /										
Farsi	57.1	55.4	49.3	47.2	51.4	44.0	44.3	55.0	56.9	50.4
English	57.1	55.4	49.3	47.2	52.5	51.7	44.3	52.5	54.9	50.1
5 /										
English	54.6	40.3	35.0	26.3	48.8	20.4	25.4	36.7	9.2	12.8



Participant # / Language(s) <sup>b</sup>	PF	RP	BP	GH	PCS	VT	SF	RE	MH	MCS
6 / English	57.1	55.4	43.7	41.5	53.6	34.3	50.7	49.8	35.3	37.7
7 / Farsi	37.1	55.4	60.6	44.4	48.0	41.2	38.0	55.0	46.4	46.5
8 / English	19.6	34.7	31.0	52.8	32.5	36.3	25.7	40.9	29.7	37.1
10 / English	47.1	42.2	49.3	38.7	43.3	58.6	57.0	55.0	45.1	55.6

Note: <sup>a</sup> Norm-based scores (NBS) are determined based on Canadian average scores (Canadian average score for each NBS subscale = 50). Better health corresponds with higher scores; scale 0 – 100. <sup>b</sup> Results are presented for Farsi and English translations of the SF-36.

Key to Abbreviations: PF = Physical Functioning; RP = Role-Physical; BP = Bodily Pain; GH = General Health; PCS = Physical Component Summary (includes PF, RP, BP, GH); VT = Vitality; SF = Social Functioning; RE = Role-Emotional; MH = Mental Health; MCS = Mental Component Summary (includes VT, SF, RE, MH)



*Figure 1.* SF-36 health survey results in physical and mental health subscales and summary scores, for participants with chronic pain (Participants 1, 3, and 5) using norm-based scores (NBS)<sup>a</sup>. a. Participant 1 subscales; b. Participant 1 summary scores; c. Participant 3 subscales; d. Participant 3 summary scores; e. Participant 5 subscales; f. Participant 5 summary scores.

Note: <sup>a</sup>Norm-based scores (NBS) are determined based on Canadian average scores (Canadian average score for each NBS = 50). Better health corresponds with higher scores; scale 0 – 100.

Key to Abbreviations: PF = Physical Functioning; RP = Role-Physical; BP = Bodily Pain; GH = General Health; VT = Vitality; SF = Social Functioning; RE = Role-Emotional; MH = Mental Health; PCS = Physical Component Summary (includes PF, RP, BP, GH); MCS = Mental Component Summary (includes VT, SF, RE, MH)

## **Qualitative Results –Experience and Management of Pain**

### **5.1. Introduction**

This chapter explains individual pain experiences and pain management strategies of Afghan immigrant women, and how these experiences and management strategies are influenced by Afghan culture. The first section of this chapter constructs a cultural model of pain *experience* for Afghan women. Then, the cultural model of pain experience is used as a framework from which I present the next section on individual pain experience. A constructed cultural model of pain *management* follows that, and is used as a framework from which I present the final section on individual pain management strategies.

The cultural model, which represents Afghan cultural perspectives about pain experience and pain management, is constructed from the literature and interviews with participants (see Tables 2 and 3, and Chapter 7, Significance of Findings in the Context of Literature). In this chapter, the cultural model is presented using data from participant interviews. To construct the cultural model of pain (experience and management), participants were asked questions about the community's cultural perspectives, not necessarily their personal perspectives. At times, participants explained that their personal perspectives were different from the perspectives of their cultural community. Therefore, the model does not reflect the internal perspectives of all participants; life experiences have influenced how much their individual pain experiences reflect the cultural model.

Table 2. Cultural Model of Pain Experience – Supporting Evidence from the Literature and Interviews

Description	Supporting evidence	
	Literature	Interviews
Pain experience is multifactorial	-	M.
Environmental factors	Aziz, 1999; Tavafian, Gregory, & Montazeri, 2008	Lisa, M., Rasa
Spiritual factors	Aziz, 1999	Lisa, M., Rasa
Biological factors	Lipson, 1991; Tavafian et al., 2008 Peterlin, 2009	M., Sheila, Zahra
Psychological factors	Kleinman & Good, 1985; Pugh, 1991; Aziz, 1999; Tavafian et al., 2008	Lisa, M., Rasa, Zahra
Factors of pain holistically blend to describe somatic experience	Devisch & Gailly, 1985; Kleinman & Good, 1985 Pugh, 1991; Aziz, 1999	Herose, Lisa, R., Rasa, Zahra

Table 3. Cultural Model of Pain Management – Supporting Evidence from the Literature and Interviews

Description	Supporting evidence	
	Literature	Interviews
Pain management is multifactorial	-	-
Environmental Factors	-	Herose, Lisa, R., Rasa, Sheila, Zahra
Spiritual factors	Aziz, 1999 Aziz, 2011	Rasa, Lisa
Biological factors	Keefe & Smith, 2002	Herose, Lisa, M., Rasa, Sheila, Zahra
Psychological factors	-	Herose, Lisa, R., Rasa, Sheila, Zahra
Factors of pain holistically blend in pain management strategies	-	R.

Note. In the constructed cultural model of pain management, information from interviews filled in gaps from the literature.

This study included primary informants (Herose, Lisa, Rasa, Sheila, and Zahra) and secondary informants (M. and R.). In the following sections, data that are contributed by specific interview participants are followed by the participant pseudonyms in parentheses. Primary informants answered specific questions about the cultural model of pain in their first interview (see Appendix D, Interview Guide Segment 1).

## 5.2. Cultural Model of Pain Experience

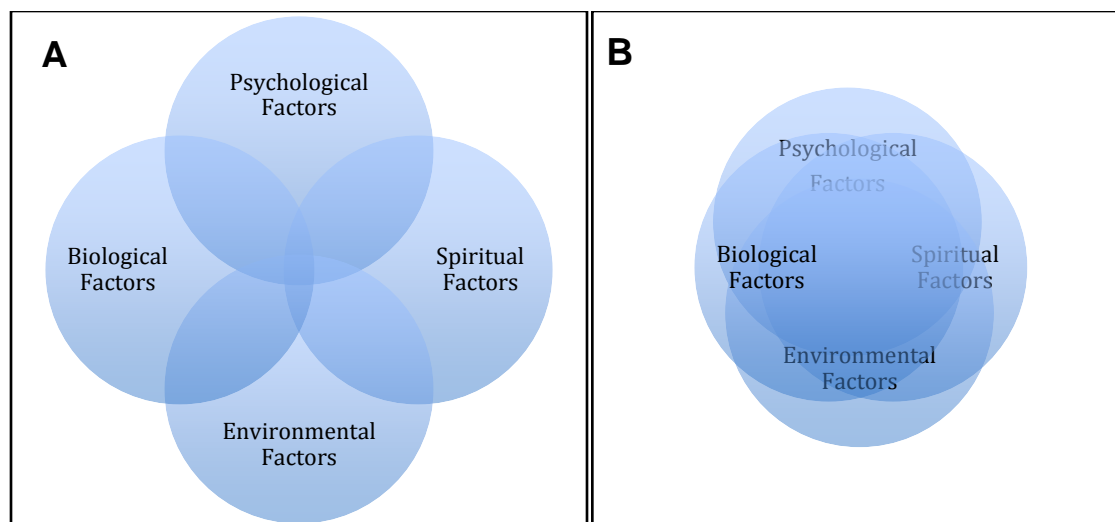
Chronic pain experience for Afghan immigrant women is “multifactorial” (M.) The definition of the term *factor* is “agent” or “circumstance etc. contributing to a result” (Thompson, 1992). Pain experience is multifactorial in that multiple factors, or agents, contribute to the pain experience. This study supports 4 factors that Afghan women attribute to their pain (see Table 2):

1. *Biological factors* – Biological factors include attributing pain to biological/organic causes (Sheila, Zahra, M.). For example, M. said, “When they do have pain or going through pain, sometimes you do hear them that it’s a part of aging or I fell and hurt myself like two years ago so maybe that’s the cause of it.”
2. *Psychological factors* - Psychological factors include attributing the chronic pain to emotions such as depression or anxiety (Lisa, Rasa, Zahra). For example, Rasa said, “And I told you maybe this [pain] is because of the stress. Maybe nothing else.”
3. *Environmental factors* - Environmental factors include attributing pain to the social environment (family conflict and social isolation) or the physical environment. (Lisa, M., Rasa). For example, M. said, “When they do have pain or going through pain... also sometimes you hear this blaming part that, oh you know, I’m having... my son did this, or I’m having an argument with my husband or wife.”
4. *Spiritual factors* - Spiritual factors include attributing the pain to *Nazar* (evil eye, *jin* (evil spirits), or punishment from Allah (the Muslim and Arabic word for God; Thompson, 1992). (M.; Lisa; Rasa)

Biological, psychological, environmental, and spiritual factors are used to explain the causes of pain for Afghan women.

**5.2.1. Holistic experience.** When Afghan women experience pain, the four factors contributing to pain experience (biological, spiritual, environmental, and psychological) are experienced together, as a whole. Therefore, I have used the term *holistic* experience to highlight the Afghan perspective of their pain experience (see *Figure 2*). The term *holistic*, or *as a whole*, means “as a unity; not as separate parts” (Thompson, 1992). Afghan immigrant women’s experiences of pain are holistic, easily encompassing multiple factors. For example, if suffering is a result of domestic abuse, pain could be attributed to biological, psychological, and environmental factors. Suffering could also be a consequence of feeling disconnected from Afghanistan, from community, or from family (Herose, Lisa, Rasa, Zahra). In such cases, somatic pain might be attributed to psychological and environmental factors.

**5.2.2. Summary of cultural model of pain experience.** Pain experience for Afghan women is multifactorial and holistic. Afghan women attributed the cause(s) of their pain to environmental, spiritual, biological, and psychological factors. These factors blend holistically in the explanations that Afghan woman gave to describe the cause(s) of their somatic pain.



*Figure 2. Categorized vs. holistic pain experience. A* Categorized pain experience - factors are within distinct categories, although there may be overlap. *B* Holistic pain experience - factors contributing to pain experience in Afghan immigrant women blend holistically, compared to *A*. The factors of holistic pain experience are not differentiated, but are experienced together, as a whole.

### 5.3. Individual Pain Experience

**5.3.1. Herose. 5.3.1.1. Pain experience summary.** Herose is a wife and mother who had left Afghanistan 22 years before the interview. Herose said that she experienced “not too much, a little bit” of physical pain as a result of being separated from her family. She did not believe that her pain had changed from when it started until the time of the interview. When asked to demonstrate her pain using the Faces Pain Scale – Revised (FPS-R), Herose pointed to the face representing a pain intensity of 0/10, saying that she tried to smile some. When asked how she felt inside, she pointed to the face corresponding with a pain intensity of 4/10. Herose said that she felt the pain in her body; however, she was unable to indicate on a body diagram where her pain was. On the Iranian Short Form McGill Pain Questionnaire (I-SF-MPQ), Herose used sensory descriptors to describe her pain (Sensory-Pain Rating Index, S-PRI = 6). She did not use any affective descriptors to describe her pain (Affective- Pain Rating Index, A-PRI = 0). Her pain intensity on the visual analogue scale was 9.6/10. She describes her evaluative overall intensity as distressing (3).



Herose talked about daydreaming while doing her housework. She daydreamed that she was at her mother's home. She struggled with the fact that they were so far away. When asked if her pain was similar to or different from the pain experienced by other Afghan women in her community, Herose said that her pain was different from other women in her community because she (Herose) was lucky that her family lived in Europe. Herose's friend was often concerned, because her family still lived in Afghanistan. Furthermore, her friend could not visit her family, whereas Herose had had opportunities to visit with family. "They all, they together they come to visit me. For short time, but not long time, for short time. But still, I think it's (.) I'm lucky than other women."

Her pain experiences made Herose want to cry. However, she said that she never cried; she held it inside. "In our language, we say we're going to (.) put in our stomach. So we don't (.) (take) anybody to talk about that." She believed that she had control over her pain and that her family benefited as a result: "Some women, they can't control their pain and maybe sometime they, make, (angry) with their kids or something. But I'm not like that. I try to, make this different... for the kids or for family."

**5.3.1.2. Herose's pain experience and the cultural model.** Herose was an Afghan immigrant woman experiencing pain within the framework of her cultural model. Her pain included psychological (emotional) and environmental factors (social environment). Although she had no biological factors in her pain experience, Herose said that she experienced physical pain in her body. On a body diagram, she could not demonstrate where the pain was. However, on the I-SF-MPQ she used only sensory descriptors to describe her pain (S-PRI =6) and no affective descriptors (A-PRI =0). Because she described her pain using only sensory terms and no affective (emotional) terms, this might indicate that Herose was experiencing the pain at a somatic level rather than at an emotional level. It demonstrated her holistic experience of pain.

**5.3.2. Lisa. 5.3.2.1. Pain experience summary.** Lisa had experienced tension headaches and migraines for about 6 years. Her migraines started when she would ride a bus home from work. The bus ride was always very loud and "crazy", and she found that noise and light started bothering her during these rides. She would squint her eyes because of the pain, but she didn't tell anyone, including her family, for the first few weeks.

A few weeks after the headaches started, Lisa realized that her headaches weren't getting any better. She told family, and a family member started driving her to work so that she didn't have to take the bus. She found that this helped. Then, Lisa changed jobs. During the first year in her new place of employment, she experienced what she called "really bad migraines". Since that first year, she had found that the occurrence and severity of her migraines fluctuated. Lisa's work was seasonal, and she found that her pain was less severe during off-seasons. During seasons of work, however, it could be "really bad".

Lisa found that her pain affected her ability to participate in her occupation and communicate with friends or family members. When she had a migraine, she squinted her eyes because of the pain. Her ears popped and she became very sensitive to sounds, smell, and light. Really severe migraines prevented her from doing her daily activities. Then, she closed the blinds, covered her head under a blanket, and lay still, trying not to vomit, faint, or even think. Having these migraines also affected her emotionally. She said that they made her more sensitive and grumpy, and she became more easily angry.

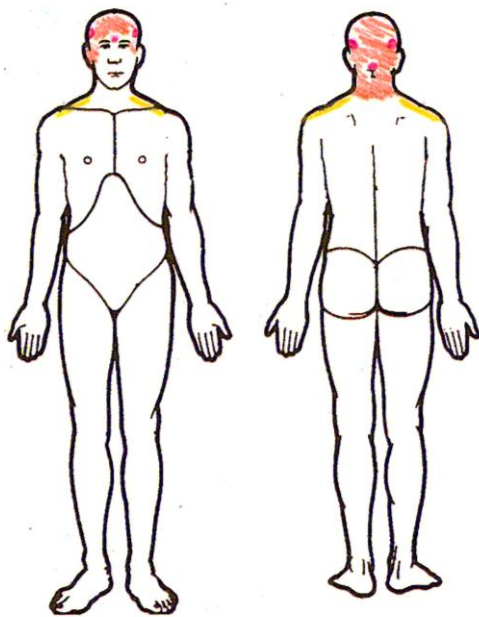
There are several things that affected Lisa's experience of pain. Often, but not always, sleeping helped to relieve the pain. Noise, light, and strong scents made her pain worse. Changes in weather may have also made her pain worse. She thought that all the reading that she had to do at work might have caused her pain. Furthermore, stressful situations such as work deadlines "can provoke the pain and they can also worsen the pain". She got migraines far more often during work than when she was not at work. However, on a psychological level, she believed that she experienced stress and anxiety at similar levels to other employees at her work. Her family doctor had suggested that perhaps the tension in her neck and shoulders caused the pain, leading to "vasorestriction" and insufficient "blood to my head". The doctor also found, upon testing, that Lisa had low hemoglobin levels. They (the doctor and Lisa) thought that this might have contributed to her headaches because of lower oxygen levels in her brain.

During the week before our first interview, Lisa experienced daily migraines. The migraines started at noon and continued to worsen until bedtime. This continued over the following week until the second interview. During the second interview, Lisa avoided movements of her head and neck such as rotation, flexion and extension. When questioned about any changes she may have experienced over the last week, she said, "Actually my neck hurts

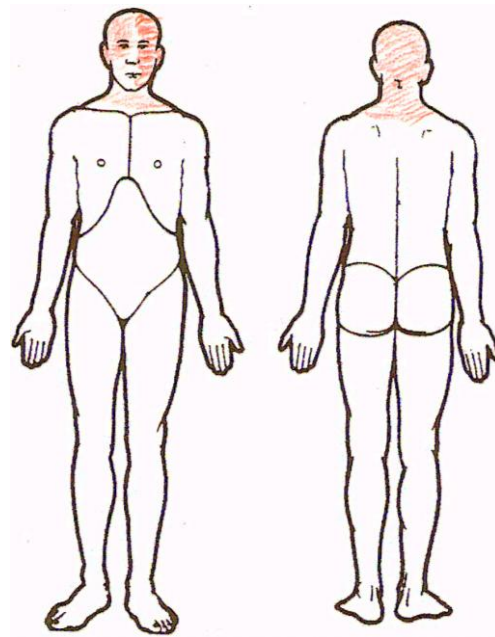
really bad. I think I slept really funny. And I feel like it's really really bad this week compared to last week."

Lisa did not believe that there was a higher purpose to her pain: "I think it's just, something that's physically wrong with you. I don't think there's like a higher meaning to pain." She said that she associated more with Canadian perspectives than the perspectives of Afghan culture. She believed that this was reflected in the way that she encountered healthcare, managed her health, and communicated with Canadian society: "There is no trouble in communication between me and the healthcare provider. There isn't a disconnect between our beliefs and what's ethical and what isn't ethical. There is like a mutual respect." However, she struggled with the fact that she sometimes had to cancel meetings with people because of her headaches. She didn't believe that everybody understood the severity of her symptoms, and this was a source of distress for her: "Some people don't understand that it's like, I have a headache to the point where I am nauseous and I'm like, heaving and I feel so sick that I can't even have any sort of light in my room."

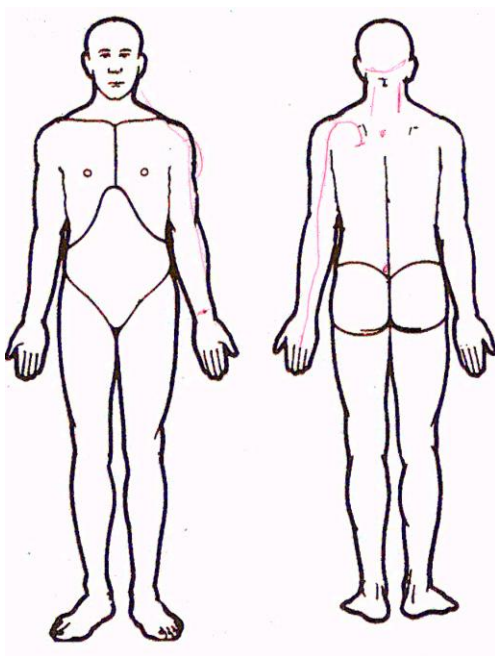
The severity of Lisa's pain increased from the shoulders and neck up to her temples (see *Figure 3a*). When she experienced a migraine headache, her pain intensity on the FPS-R was 8/10. When she had a migraine, Lisa's S-PRI = 13 (sensory) and her A-PRI = 11 (affective) on the SF-MPQ. Lisa's pain intensity on the visual analogue scale was 8.8/10. She described her evaluative overall intensity on the SF-MPQ as distressing (3) (see Table 4).



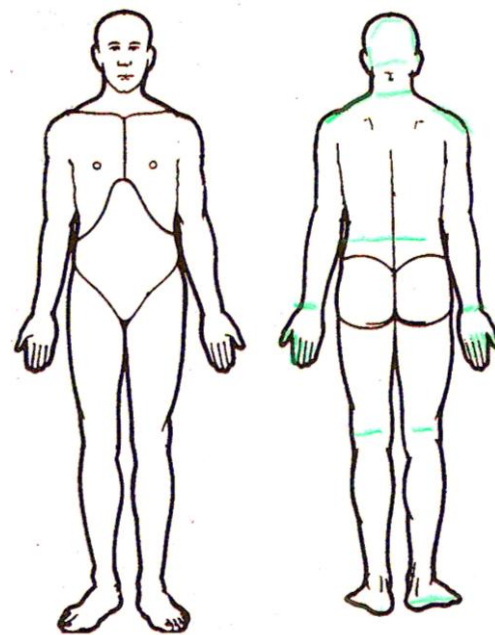
a.



b.



c.



d.

*Figure 3.* Body diagrams of pain distribution. a. Lisa's body diagram. b. Rasa's body diagram. c. Sheila's body diagram. d. Zahra's body diagram.

Table 4. Responses to Questionnaires in Part 2 (n=5, interviewees with chronic pain) – Faces Pain Scale – Revised (FPS-R) & Short-Form McGill Pain Questionnaire (SF-MPQ)

Pseudonym (Language)	FPS-R		SF-MPQ				
	Present	When in Pain	S-PRI	A-PRI	T-PRI	PPI (when in pain)	EOI
Herose							
(Farsi)	-	4/10	6	0	6	(9.6/10)	3
Lisa							
(English)	0/10	8/10	13	11	23	(8.8/10)	3
Rasa							
(Farsi)	0/10	8/10	16	7	23	(8.7/10)	3
Sheila							
(Farsi)	2/10	6/10 or 8/10	18	3	21	-	1, 2
Zahra							
	6/10	-	-	-	-	-	-

Note: Results are presented for Farsi and English translations of the SF-MPQ. S-PRI = Sensory – Pain Rating Index; A-PRI = Affective - Pain Rating Index; T-PRI = Total – Pain Rating Index; PPI = Present Pain Intensity; EOI = Evaluative Overall Intensity

**5.3.2.2. Lisa’s pain experience and the cultural model.** Lisa described her pain in mostly biological terms. This included attributing her headaches and migraines to eyestrain, vasoconstriction, and low oxygen levels. Environmentally, she stated that cold weather, noise, light, and strong scents could make her pain worse. Although she did not describe a direct connection between these variables and the cause of her pain, she attributed her pain to environmental factors indirectly because her pain started in the loud and “crazy” bus – suggesting that “the loud and crazy bus” was in fact a biological factor because noise levels could affect her biologically. Psychologically, she admitted that stressful situations could

provoke the pain. Therefore, although her explanation of pain was primarily biological, Lisa experienced pain that she attributed to biological, environmental, and psychological factors.

Lisa's conscious personal perspectives of pain differed from the Afghan cultural model, but her experience of pain could be considered a mix of conforming to and differing from the cultural model. She mentioned that stressful situations (a psychological factor) could provoke her pain, and she used predominantly affective descriptors to describe her pain (A-PRI = 11, maximum A-PRI score is 12). A high A-PRI score suggests that the psychological factor was an important aspect of Lisa's pain. However, she thought of her pain in only biological terms: "I think it's just, something that's physically wrong with you. I don't think there's like a higher meaning to pain." In believing that there was no higher meaning to pain, Lisa disregarded the spiritual factors that her cultural model attributes to pain.

**5.3.3. Rasa. 5.3.3.1. *Pain experience summary.*** Rasa was a mother who worked inside and outside the home. Following the pattern of her previous lifestyle in Afghanistan, she was usually on the move. She said that life forced women in Afghanistan to work hard, and in Canada, although "nobody can force me," she had worked hard even when she was not feeling well. The discipline that she learned while growing up was still a strong part of who she was. Rasa had suffered from migraine headaches for 5 years. These migraines used to occur three to four times per month. At the time of the interview, they were occurring less frequently. Without medication, Rasa's pain started on the left side of her neck and traveled up to her left eye. Although she experienced pain in both ears, the left ear was worse than the right. Light bothered her eyes, and she experienced nausea and an upset stomach. She felt somewhat better after "running to the washroom", and she found that vomiting also brought some relief. As a result of these symptoms, she could not eat for 24 hours.

When Rasa took medications for her headaches, she often napped for a few hours after taking the medication. She found that, after this, she woke up feeling fresh but weak. Her head felt heavy, but this resolved within about 12 to 15 hours. She could not eat anything during these 12 to 15 hours.

On the FPS-R, Rasa experienced a pain intensity of 8/10 when she was about to have a migraine, before she had taken her medications. On the I-SF-MPQ, her S-PRI = 16 (sensory) and her A-PRI = 7 (affective). Her present pain intensity was 0/10 on the visual analogue scale at the

time of the interview, and 8.7/10 when she experienced migraines. Her evaluative overall intensity over the last day had been no pain (0) during the time of the interview, but distressing (3) when she had a migraine (see Table 4).

Rasa found that her migraines occurred often when she had worked long periods of time on the computer, or when she had worked long hours in standing positions. Sometimes she woke up with migraine symptoms. She also attributed her pain to stress, stating that she was more likely to get a migraine when she had experienced a lot of stress. On stressful days, she felt “butterfly in my stomach”, weakness, and “light pain” (pain of low severity). Sometimes these symptoms led to migraines. Rasa had begun to believe that the pain was also caused by her depression. She said that she struggled with this because emotional pain is difficult to explain and difficult to treat.

When Rasa was alone, she said that she had a habit of thinking too much. She missed her extended family and Afghanistan, which she had not seen for 14 years. She said that, since her family had settled into Canadian life, she struggled with the acculturation of her children. She attributed this struggle to her pain experience.

**5.3.3.2. *Rasa’s pain experience and the cultural model.*** Rasa attributed her pain to multiple factors. Possible biological causes of her pain included spending long periods of time on the computer (eye strain) and working long hours in standing positions. A possible environmental cause of her pain was her social environment, as she attributed her pain to the acculturation of her children; although it was not explicitly articulated, Rasa may have interpreted the acculturation of her children as denial and rejection of herself and the cultural values that were important to her. Possible psychological causes of her pain included the stress related to acculturation of her children, other stressful situations, and depression.

Rasa embraced the cultural model of pain as she explained her own pain experience, attributing her experience to multiple factors. However, in distinguishing between emotional pain and physical pain, Rasa used a framework to describe her pain that is incongruous with the cultural model (see Chapter 7, Somatization vs. Holistic Experience). This may have been a result of the discussion I initiated with her concerning physical vs. emotional pain, or a consequence of her interactions with Canadian society.

**5.3.4. Sheila. 5.3.4.1. Pain experience summary.** Sheila came to Canada as a widow. She believed that the problems she encountered in Afghanistan, including changes instituted by the Taliban, had an effect on her mental health. She said that she used to think she was going crazy, but she thanked God that she is okay. When she left the Taliban situation in Afghanistan and moved to Canada, she felt very free. Although she admitted that she still had some difficulties with Canadian life at the time of the interview, for the most part things were much better. She believed that she was a strong person, and she was glad that she left “that worst place” of war at a time when women were being killed daily.

Sheila enrolled her children in school promptly when she moved to Canada. She wanted to go to school herself, to learn English, but was unable to do so in the best interest of her children. She regretted that she was not able to learn better English when she first came to Canada, but her situation as a single mother had been very difficult. She said that everything she had been dealing with came together and “stuck in my chest.”

Because she spoke only broken English when she came to Canada, Sheila was forced to find jobs that required physical labor. She found that the new work was very hard on her body. This was compounded by the fact that she had not done much physical work in Afghanistan. Because language requirements forced her out of desired employment, she attributed the cause of her pain to language, saying, “If I tell you the truth, it started from my language.”

Sheila started experiencing pain at work more than 10 years before the interview. Her work involved lifting and pushing heavy objects. The pain started in her shoulder, and slowly got worse and worse. When the pain started, she described that her heart was also pumping badly. Concerned for her health, Sheila went to see a doctor. The doctor confirmed after testing that the problem was not her heart. However, he thought that her symptoms may have been related to a muscle problem, and recommended that she slow down at work. Because of job requirements, Sheila felt that she was not able to slow her work pace. Therefore, she continued to work for a number of years at the same pace as before. She believed that her body got used to the work, but she also mentioned that, because she was a single mother, she continued to push herself. She felt that she was doing what was needed for her family. Then, a few years before retirement, Sheila had to slow down because of her pain. She attributed the change, in part, to age. She said that, by the time she finished working, she could not do it anymore.



Sheila attributed her pain to multiple factors. She said, “Everything affects the human body.” She thought that her past nutritional intake and the circumstances she left in Afghanistan might have contributed to her current physical difficulties. She said that she had given her life, strength, and energy to her children over the years, sacrificing many things for them. Furthermore, she did not think that she had adequate clothing for her first Canadian winter. She found the cold weather was hard on her body, and she attributed the pain, in part, to the cold.

When Sheila had pain, it usually started at the posterior shoulder and scapula, bilaterally. It traveled down the outside of her arms, along the deltoids and biceps brachii, over and through her wrists and toward her fingers. It also traveled up her neck and along her hairline. In the past, when she worked, the pain would continue to worsen throughout the day.

Having physical pain had affected Sheila mentally and emotionally. The pain had affected her concentration. For example, if she had pain while making a meal, she would sometimes get confused and miss ingredients. When she had pain, Sheila also said that she was unable to talk well because of her emotion. For example, when she had pain while working, if somebody tried to talk to her she said she wanted to cry. Instead, she turned her face and went away.

The day before our interview, Sheila had visited the doctor for her pain. The pain had started two days before the interview, and was at its worst one day before the interview. At one point during the interview, Sheila said that she felt a little bit of pain. Another time, she said that she felt good as a result of my visit: “Ya, because I see you, I talk to you. This is a good thing. You can visit all the time.”

On the I-SF-MPQ, Sheila described her pain using primarily sensory descriptors but also affective descriptors (S-PRI=18, A-PRI=3). Using the visual analogue scale, Sheila described how her pain started as nothing and would gradually get worse throughout the day. Her overall evaluative intensity of pain experience for the day of the interview was mild (1). The day before, she said her pain was discomforting (2). On the FPS-R, she described her pain at an intensity of 2/10. She said that it sometimes went up to 6/10 or 8/10 (see Table 4).

**5.3.4.2. Sheila’s pain experience and the cultural model.** Sheila attributed her pain experience primarily to biological factors. She believed that her pain may have been caused by physical labor, a muscle problem, and nutritional deficiencies. She also attributed her pain to the circumstances she left in Afghanistan, although it was unclear whether she meant to attribute this

to biological, psychological, and/or environmental factors. Based on the context of the interview conversation, she seemed to attribute the pain to biological factors. She also attributed her pain, in part, to cold Canadian winters, an environmental factor. Finally, Sheila attributed the pain to language. Although she did this, she did not mean that language literally caused the pain, but rather that indirectly it caused pain because it forced her to find a job doing physical labor.

Sheila's experience of pain both agrees and disagrees with the cultural model of pain. Sheila viewed her pain holistically, thereby internalizing of the cultural model: she said, "everything affects the human body." However, Sheila attributed her pain primarily to biological factors. Although she thought that her pain may have, in part, been caused by an environmental factor (cold Canadian winters), one could argue that this was also a biological factor rather than an environmental factor, as cold weather could have affected her body biologically.

**5.3.5. Zahra. 5.3.5.1. Pain experience summary.** Zahra was a woman who held strongly to Afghan traditions. This was evident in the way that she decorated her home. Furthermore, for each of the two interviews in her home, Zahra displayed traditional Afghan hospitality by preparing an assortment of food. She also demonstrated her traditional values by remarking that some of the women from her community were wearing their *hijabs* (head coverings) too far back on their heads, and blouses with sleeves that only went to the mid-arm. She disapproved of these changes: "Me never, I'm scared about my God." She upheld the values that were instilled by her family in Afghanistan. Zahra's mother's words had stayed with her:

My mom before she told me, Zahra, my daughter, you nice. No go outside. Just lived your kids at home, you go different place. I'm listen my mom. I'm listen my father. I'm scared about my father my mom.

Zahra attributed her pain, which started three years before the interview, to multiple factors. She believed that her thoughts may have contributed to her pain experience: "Ya, after 2010, too much thinking, then I have, sore and sick." She also said: "I can't, no sleep fast, I thinking thinking then sleep. Then after wake up I have sore headache." She said that being sad made her sore. Zahra also believed that birth control medication, administered through needles into her arm, may have caused the pain. Her doctor had advised Zahra to stop taking the needles because they were causing "too much trouble". Three months after stopping these

administrations, Zahra experienced headaches and backaches: “I’m okay. No headache, no nothing. After this take this needle, make me trouble.” Zahra attributed the pain to these needles nine times over the course of two interviews. She also believed that the pain may have been caused from having children, experiencing change, falling down two times, her relatively recent weight gain, or problems with her teeth. During the interviews, she mentioned each of these possible causes for her pain more than once. She also mentioned that both she and her friends were okay before moving to Canada, but now that they had moved to Canada they were having problems.

During both interviews, Zahra sat on her legs on the floor. Although she repeatedly mentioned that sitting in this position for more than 10 to 15 minutes caused her pain, she started and remained in this sitting position for the majority of both interviews. Two times during the interviews Zahra made sounds expressing her pain as she repositioned her sitting position on the floor. She thought that this pain from sitting might have been a result of using birth control needles or from falling. She said, “After ten minute, I can’t walking. I don’t know for now just for, before now, maybe about this my needle.” Another time she said, “Just I sit, I have a little bit problem. I don’t know, maybe about this needle, about fall down?”

No other activities aggravated Zahra’s pain. When she had no visitors, she often worked around her home. She experienced no pain when she was doing cooking or cleaning, although she admitted that if she worked really hard, she would be sore.

The distribution of Zahra’s pain was widespread. She had pain in her right foot, bilateral wrists and fingers, bilateral shoulders, her lower back, her neck, and her head. She said that sometimes the pain started in the front of her head and spread behind the ear to the base of the neck. Sometimes the pain traveled up and down the side of her face to her jaw and teeth. Despite describing pain on the side of her face, Zahra only drew on the posterior view of the body diagram (see *Figure 3d*). Zahra’s pain intensity, represented with the FPS-R, corresponded to an intensity of 6/10. She said that she didn’t have headaches every day, just sometimes. Because of time limitations, and Zahra’s inability to read English or Farsi, neither the I-SF-MPQ nor the SF-MPQ was completed.

**5.3.5.2. Zahra’s pain experience and the cultural model.** Zahra’s pain experience agreed with the cultural model of pain. She experienced and explained her pain using multiple factors. The biological factors that she thought caused her pain included past use of birth control

needles, having children, falling down, weight gain, and problems with her teeth. Psychological factors causing her pain included thinking too much and being sad. An environmental factor that she attributed to her problems was the move to Canada. Furthermore, having children, weight gain, and problems with her teeth may also be considered psychological factors of Zahra's pain, because she expressed through the interviews that each of these difficulties had caused her distress.

#### **5.4. Summary of Pain Experience**

Afghan cultural perspectives influenced how Afghan immigrant women in this study experienced their pain. The cultural model of pain contributed to their individual lives on a continuum of very strongly to very little, depending on how much they internalized or disregarded the cultural model. For example, whereas the cultural model demonstrated that pain experience for Afghan women is multifactorial and holistic, Lisa and Sheila experienced and explained their pain from more biomedical perspectives. In contrast, Herose, Rasa, and Zahra had more holistic pain experiences relating more closely to the cultural model of pain. The degree of internalization of the cultural model (meaning, in this context, the degree that cultural perspectives affected their pain experience) may have been influenced by a number of different variables. This study was not designed to explore the variables that influenced the degree of internalization of the cultural model. Acculturation and integration into Canadian society may have influenced whether Afghan women conformed to or differed from their cultural model, but more research is needed to explore these and other variables.

#### **5.5. Cultural Model of Pain Management**

Like the meaning and experience of pain, pain management for Afghan women is multifactorial and involves the influence of environmental, psychological, spiritual, and biological factors. The following pain management strategies demonstrate how pain management may involve one or more of these factors:

1. *Environmental (social environment) & Psychological factors* - Sharing pain with other women is one of the dominant management strategies that women in this study used. Afghan women share their pain with each other in order to provide each other with verbal support and encouragement, to experience a

connection with each other, as a method of consciously attending to the pain, and in order to share and find new treatments for their pain. The sharing of treatments may include, among other things, sharing home remedies such as teas and balms, and where in the city to go for help. (Herose, Lisa, R., Rasa, Sheila, Zahra)

2. *Spiritual factors* - Afghan women believe that spiritual practices are important for pain management, including but not limited to methods to ward off the evil eye (Rasa) and various prayer rituals (Lisa, Rasa). Attributed causes for pain also warrant prayer, as Lisa explained: “It’s the traditional view of pain that some people have... the older generation. They would believe that pain is a form of punishment from God for doing something. And they may think that there is healing through prayer.”
3. *Biological/Psychological/Environmental factors* - Rest is another pain management strategy, although an Afghan woman’s ability to rest depends on family expectations and roles, and the level of support she receives at home. If a woman’s role at home does not allow her to rest, she is forced to work despite her pain (Herose, M., Lisa, Rasa, Sheila).
4. *Biological factors* - Afghan women may attempt to manage their pain with biomedical treatment strategies, through healthcare access and the use of medications. In seeking help, they often seek to find cures for their pain. They expect that the healthcare professional will cure or alleviate their problems, and they are more likely to think that treatment should be short with quick relief (Lisa; M., R.). Although this is viewed primarily as a biological factor, the next paragraph demonstrates how medications may also be viewed as a spiritual factor in pain management.

**5.5.1. Holistic management.** Afghan women manage their pain holistically. For example, they may participate in healthcare treatment strategies using the same perspectives they use for other treatment strategies – as a matter of faith. To demonstrate, Afghan women may not think of medications in terms of basic science, but rather as something with specific healing qualities. In speaking of how Afghan women may view medications, R. said, “I don’t want to

use the word magical, but it does [have] a lot of mystery around it.” R. related this to a story he heard of a woman who visited the doctor. Instead of filling the prescription at a pharmacy, “she took the prescription paper, and she broke it into pieces, put it into the bowl with water, and consumed it.” Doing so was using “a model that is used, traditionally. You write prayers and... either run water over it, or whatever you do with it.” (R.) When this woman consumed her “medications” this way, she was blending pain management strategies that come from biological, spiritual, and (social) environmental factors. In drinking her prescription paper, this woman “is an example where these two understandings come together and get confus[ed].” (R.) This woman may have used similar faith-based methods of consumption in her use of spiritual rituals and home remedies. Essentially, she viewed the management of her health in a holistic way.

**5.5.2. Summary of cultural model of pain management.** Pain management for Afghan women is multifactorial and holistic. Afghan women manage their pain using strategies that target environmental, spiritual, biological, and psychological factors. These factors blend holistically in the strategies that Afghan women use to manage their pain. Three important pain management strategies are identified: (a) sharing pain with other women, (b) resting, (c) and seeking a cure.

## **5.6. Individual Pain Management**

**5.6.1. Herose. 5.6.1.1. Pain management summary.** Herose used several management strategies to deal with her pain. One way that she managed her pain was by keeping herself busy: “Make me busy (til) I forgot that. So I don’t think about (that).” To distract herself, Herose worked at home. She also went for drives with her husband. Sometimes she also distracted herself by listening to music: “I try to listen that, to forget that.” She tried to remain optimistic; sometimes she thought the pain made her strong, and that “some day is gonna be, good.” Another important and frequently mentioned method that Herose used to manage her pain was talking to other Afghan women:

If they are not busy, then I, talk a little bit. So it’s going to help me (up) a little to don’t think about my family.... For me is good, when I talk (.) to somebody. And maybe for them too?

Herose also managed her pain through the use of medications, going to the doctor, or going to bed.

**5.6.1.2. Herose's pain management and the cultural model.** Herose's experience of pain involved psychological and environmental factors. To manage her pain, Herose addressed these psychological and environmental factors of her pain; her primary pain management strategies included distracting herself and talking to friends. She also chose to think positively (psychological management), took medications and went to the doctor (biological management), and went to bed (biological, psychological, and/or environmental management). With the importance of sharing pain as a form of her pain management, and by addressing multiple factors, Herose followed her cultural model of pain management.

**5.6.2. Lisa. 5.6.2.1. Pain management summary.** Lisa had made many changes to her lifestyle in an attempt to control her migraine headaches. She said that she sought medical treatment and tried to heal her pain. In this way, she believed that she managed her pain similarly to the Afghan community: "I think anyone with pain seeks some sort of a healing." Lisa's family doctor put her on muscle relaxants for a year to treat the tension in her neck and shoulders. Lisa believed that the muscle relaxants "screwed me up for a year. I was always drowsy, always tired, had horrible attention." At the time of the interview, she said that she took migraine pills for her pain, but "sometimes those don't even help." She had also tried various other medications suggested by her doctor, except medicinal marijuana, which her family disapproved of. She had also made diet changes, as suggested by her doctor, in order to increase her body's iron levels. She had tried to be physically active. She had tried stress management. She had been careful to get eight hours of sleep and to stay properly hydrated. She bought an ergonomic pillow to improve her sleep posture. She wore reading glasses "because maybe it has something to do with my vision." She tried to avoid scents and perfumes, as they could give her "crazy headaches." When she had migraine headaches, she avoided light and tried to find a quiet place. She told her family so that they could keep the noise level down.

At the time of the interview, Lisa's main forms of pain management included the use of medications and sleep. She had also been going to the gym, and since starting she had noticed that her headaches and the tension pain in her neck and shoulders had not been as severe. She planned to stick to her newest exercise regime by going to the gym every few days. Despite actively engaging in the process to control her pain, Lisa still found her headaches puzzling: "I changed everything in my lifestyle trying to better it, and I don't know, I don't know what it is."

**5.6.2.2. Lisa's pain management and the cultural model.** Lisa took initiative for her health and made multiple lifestyle changes in an attempt to manage her pain. As Lisa experienced her pain primarily on a biological level, she also tried to manage her pain primarily on a biological level. However, because she thought stress might have provoked her pain, Lisa also addressed her psychological health by undergoing stress management.

Lisa's pain management strategies suggest that she disregarded the cultural model of pain management. She did not appear to share her pain as a management strategy. Instead, she said that the reason she shared her pain with family was so that they could keep the noise level down. (She also did not share her pain when it first started - see Lisa Pain Experience Summary.) Unlike the Afghan women cultural model of pain management, Lisa did not seek a cure as she interacted with the healthcare system; she actively engaged in the process to manage her pain.

**5.6.3. Rasa. 5.6.3.1. Pain management summary.** For pain management, Rasa liked to participate in activities that she found relaxing or distracting. She enjoyed walking, and found it relaxing to spend time outdoors when it was quiet. She also liked to listen to loud Afghan music and go shopping. Sometimes she asked family members to give her a massage, as she found this helped. Other times she rubbed the painful area herself. She also moved her neck to alleviate the pain.

Discussing pain with other women was very important to Rasa. This involved not only visiting friends and connecting with them, but also the process of talking about her pain. She found that "complaining again and again" was important, even if she was not getting any better. Rasa said that everyone knew about her pain. With clarification, "everyone" included Rasa's family members only. Rasa did not tell people at work about her pain. She also did not tell other women in her community about her pain, unless they were discussing specific topics related to leaving Afghanistan and immigration: "I don't talk to anybody, about it, unless they, somebody talks about it and we say yes we are depressed, and this and that. Or, or it's a different country, or these are all the problems."

When the migraines first began, Rasa tried to take over-the-counter analgesics without experiencing any relief. The effects of the migraines would last up to twenty-four hours. At the time of the interview, Rasa had strong medications for her migraine headaches. With these medications, recovery from the migraines took 12 to 15 hours. When Rasa first started using the



migraine medication, she said she used to try to get by without it, believing that she shouldn't take it unless absolutely necessary. She said that she would wait, telling herself "I'll be okay." At the time of the interview, because the pain could be very bad, she took the medications as soon as she felt the migraine symptoms begin to develop.

Seeking help through the healthcare system was an important part of Rasa's pain management. She had seen doctors and a specialist for her migraine headaches. At the time of the interview, she used medications whenever she had a migraine. Sometimes she slept for a few hours after taking her migraine medications. When she did this, she placed hot pads over her ears and the side of her face. She also put eye pads over her eyes and, when possible, turned off any lights in the room. If she was working and could not sleep, she tried to slow down or rotate tasks if the current activity was exacerbating her pain:

Before I was continuing, doing the same thing that I was doing but, I think it's age problem also. I cannot manage the pain anymore. So right away I do something different like, before if I was sewing, and I had that headache, I was continuing doing it.... And if I had cleaning I have to finish cleaning, if I have ironing I have to finish this. But right now I cannot do that anymore.... I change that.... I don't want to kill myself so I have to slow down a little bit. If I cannot do it, I'll leave it for another day. And this is what I'm doing now.

Although Rasa had slowed down when she has migraine headaches, she continued to push herself regularly on other days. She said that if she slowed down a little bit, or didn't think too much, she might not get migraine headaches as often. However, staying busy was her welcome distraction from thinking too much. Furthermore, she admitted that she was afraid that slowing down might result in weight gain.

**5.6.3.2. *Rasa's pain management and the cultural model.*** In many ways, Rasa's pain management was similar to the cultural model. Sharing pain was an important part of her pain management (environmental and psychological management). Relaxation and distraction were other management strategies that she used (psychological), although Rasa had a hard time resting because doing so negated the distraction of being busy. Her migraine pills were, in essence, a "cure" (a short treatment with quick relief) for her migraine headaches. Although she still experienced symptoms with these medications, they made her pain symptoms more tolerable.

**5.6.4. Sheila. 5.6.4.1. Pain management summary.** Sheila used various strategies to manage her pain. Most significantly, she avoided activities that used to cause her pain. She no longer worked outside the home, and she did her housework more slowly than she used to. She found that, when she took it easy, she was able to go without pain. However, if she did too much housework in one day, the pain started again. When she did experience pain, she rested: “I don’t do it if I’m not feeling good.” Within about two days of resting, the pain was usually gone.

A friend recommended physiotherapy to Sheila. When she first went, Sheila was able to see a massage therapist to loosen her neck and shoulder. After that, the physiotherapist gave her exercises that she did for her back and head. In fact, exercises, walking, and stretching were a daily part of Sheila’s routine. She used to attend yoga classes, but at the time of the interview she did her own yoga routine about once a week at home. She did not take any medications.

Sheila also had other pain management strategies. She drank ginger tea to alleviate her back pain. Sometimes she massaged her hands with cream. Because cold temperatures exacerbated the pain in her hands, she covered her hands when she was sleeping; in wintertime she also wore gloves to bed. She had sought help through the healthcare system as well. Over the years her doctor had sent her for multiple tests. The results had always been inconclusive, including a negative test result for carpal tunnel syndrome.

Sometimes Sheila felt like everything was okay. At other times her situation felt hopeless. During these times, she had difficulty sleeping if the pain was really bad. She found that, during these times, instrumental music helped. Another management technique that she used was meditation. Meditation was one of Sheila’s top choices for coping with her pain. She said that meditation was very helpful, as it cleaned her mind. Sheila had also stopped watching the news. She said she could not take all the bad news from Afghanistan and other places around the world.

Sheila recommended that anyone with chronic pain should have hobbies. Hobbies brought meaning, relaxation, and happiness to her days. She thought that hobbies were the best strategy for dealing with pain: “You are clean with every emotion and mental and body and everything’s problem is gone. Just you are in some place yes, to do something.”

Sheila felt very lonely when she came to Canada. In her first years, she felt that she had no one to share problems with (including listening to their problems). She did not feel connected to her cultural community. She said that she did not think about it too much because her

children, whom she had been very proud of, had always been her main priority. Regardless, she believed that being disconnected from one's roots and those who share the same language might be one of the worst situations that Afghan immigrants or any immigrants may face. At the time of the interview, she shared her pain with no one except her children. Furthermore, her children only knew about her pain when it was "very bad pain".

**5.6.4.2. Sheila's pain management and the cultural model.** Although Sheila attributed her pain experience primarily to biological factors, she managed her pain across multiple factors. She embraced aspects of her cultural model of pain while disregarding other aspects of the model. Management strategies that Sheila used that were also management strategies in the cultural model included rest and home remedies (e.g., ginger tea). Sharing pain was an important cultural management strategy that Sheila did not participate in. However, it was because Sheila felt disconnected from her cultural community that she did not participate in this management activity. She expressed that sharing her pain during the interview helped her (see Sheila Pain Experience Summary). Activities that Sheila did to manage her pain, which diverged from the cultural model, included participating in exercise, stretching, yoga, and meditation. Sheila did not take any medication for her pain. Instead, Sheila made lifestyle changes to manage her pain.

**5.6.5. Zahra. 5.6.5.1. Pain management summary.** Zahra managed her pain in multiple ways. She believed that activities such as doing laundry, working in the garden, going outside, and going for long 1 to 2 hour walks were good for her. She also found that it helped when her husband or children applied cream and gave her a massage. Because they thought that her headaches might be related to problems with her teeth, she had also had teeth removed. Having her teeth removed had been a very difficult and emotional process for Zahra.

Although Zahra's pain started in 2010, she waited one year before going to the doctor. She said multiple times that she did not like to visit the doctor: "I'm shy, maybe (.) ya, I don't like it"; "I'm doesn't like going to doctor every day talking talking; too many people go doctor"; and "I don't want go every week and the doctor; I can't... Me no doesn't like go different place." She said that when she visited the doctor about her pain, he gave her medications. The medications that she took included ranitidine hydrochloride, ferrous sulfate (for fatigue), and ibuprofen. Zahra demonstrated little understanding about the purpose of each of these

medications. She also stated that she took her medications inconsistently for a number of reasons. Sometimes she forgot to take medications, but often she did not want to take the medications and did not think she needed them. She expressed her thoughts about medications multiple times during the interviews: “I have too many medicine; sometime I put in the garbage”; “sometimes I say okay, I go to sleep... Maybe I’m okay; then I go... nap a little bit, then I’m okay no take it”; “because no good every day (didn’t) good idea, every day I take medicine, doesn’t like me”; and “sometime I take it, sometime no take it; I say I don’t want, I don’t know.” The doctor had also given Zahra dietary restrictions because of her sore stomach. Zahra said that she sometimes followed his advice.

Zahra felt very alone in managing her pain. She said that her husband did not like it when women talked too much, and one of her friends no longer visited: “I have other my friend, before she came my house. For now no came my house. Ya, no came.” However, Zahra said that when her friends talked to her, she also talked to them. In her loneliness, she sought comfort through prayer and faith: “Oh my God, please you can help me I have sore in my shoulders, I have sore my back.”

**5.6.5.2. Zahra’s pain management and the cultural model.** Zahra’s pain management strategies did not follow the cultural model in that instead of rest, activity helped Zahra to manage her pain. In most other ways, Zahra managed her pain in ways that reflect the cultural model. For example, sharing pain continued to be one of her important treatment strategies. Although she did not always have someone to share her pain with, she shared pain with friends when they were available. Zahra had not actively engaged in the process (e.g., through diet changes) to manage her ulcer(s). There may be three reasons for this: (1) In following with the cultural model, she may have been looking for a cure and may have expected treatment to be short with quick relief; (2) she did not understand or agree with the treatment strategies given by her doctor; and/or (3) she did not have a trusting relationship with her doctor. Zahra was irregular in her use of medications; despite her doctor’s instructions, she did not believe that it was a good idea to take medications every day.

## **5.7. Summary of Pain Management**

Afghan cultural perspectives influenced how Afghan immigrant women in this study managed their pain. The cultural model of pain management contributed to their individual lives on a continuum of very strongly to very little, depending on how much they conformed to or

differed from the cultural model. The constructed cultural model of pain management for Afghan women is multifactorial and holistic; cultural management of pain also includes sharing pain with other women, resting, and seeking a cure. Herose, Rasa, and Zahra managed their pain in many ways that align with this cultural model; Sheila embraced some aspects of the cultural model and did not embrace other aspects; and Lisa did not internalize or use most aspects of the cultural model of pain management. The degree of internalization of the model (meaning, in this context, the degree that cultural perspectives affected Afghan immigrant women's pain management) may have been influenced by a number of different variables, including exposure to the Afghan cultural community vs. integration into Canadian society. However, more research is needed to understand these phenomena.

**Table 5.**

**Participant Pain Experience, Pain Management, and Affiliation with the Cultural Model of Pain (Part 2, n=5, interviewees with chronic pain)**

Pseudonym	Pain experience	Pain management	Affiliation with cultural model
Herose	Pain from missing family – attributed pain to psychological and social factors	Managed pain through busyness, car drives, listening to music, remaining optimistic, sharing pain with other women, medications, rest, healthcare access	Pain experience – high affinity Pain management – high affinity
Lisa	Pain from tension headaches and migraines – attributed pain to biological and psychological factors	Managed pain through medications, physical activity, stress management, monitoring sleep & hydration, using a ergonomic pillow for sleep posture, reading glasses, avoiding scents, healthcare access	Pain experience – low affinity Pain management – low affinity
Rasa	Pain from migraines – attributed pain to biological, psychological, and environmental factors	Managed pain through relaxation, music, shopping, massage, sharing pain with other women, medications, rest, healthcare access	Pain experience - moderate affinity Pain management – moderate affinity
Sheila	Pain from repetitive muscular strain – attributed pain to biological and environmental factors	Managed pain through activity avoidance, music, meditation, hobbies, physiotherapy, exercises, stretches, massage, walking, home remedies, healthcare access	Pain experience – low affinity Pain management – moderate affinity
Zahra	Pain is widespread for multiple reasons – attributed pain to biological, psychological, and environmental factors	Managed pain through activity, walks, massage, teeth removal, medications, sharing pain with other women, prayer	Pain experience – high affinity Pain management – moderate affinity

**Table 6.**

**Afghan Women Cultural Model of Chronic Pain Experience and Chronic Pain Management**

Chronic Pain Experience	Chronic Pain Management
Causes of chronic pain are multifactorial: pain is attributed to biological, psychological, environmental (physical and social environment), and spiritual factors.	Pain management is multifactorial: it addresses biological, psychological, environmental (physical and social environment), and spiritual factors.
Chronic pain is experienced holistically. Biological, psychological, environmental, and spiritual factors are not differentiated, but experienced together, as a whole.	Chronic pain is managed holistically. Biological, psychological, environmental, and spiritual factors are managed together, as a whole.

## Chapter 6

### Qualitative Results - Barriers in Pain Management

#### 6.1. Barriers in Healthcare Access

Barriers to pain management for Afghan immigrant women are identified in this chapter. As this study aims for relevancy for healthcare professionals, barriers to pain management in the context of healthcare access are highlighted. Many Afghan immigrant women access the Canadian healthcare system. Some women access healthcare regularly, whereas others believe that it is best to avoid the healthcare system if possible (Zahra). Patients' understanding of the healthcare system may be influenced by their previous exposure to healthcare in Afghanistan or elsewhere. For example, women who lived in rural areas of Afghanistan may not have had medical facilities to rely on. As healthcare was not available to them in Afghanistan, women who came from rural areas may seek help through other avenues before seeking medical attention for their pain (M., Lisa, Rasa).

Many of the women in this study accessed the healthcare system regularly. Two of the main barriers that they and their community encountered while accessing the healthcare system included communication difficulties and differing perspectives on how to treat pain symptoms. This chapter addresses these two factors.

**6.1.1. Communication difficulties.** Patient histories are important in healthcare interactions and treatment decisions. However, “getting that might be a challenge from them, because they [Afghan immigrant women] might not give you everything.” (M.) There were five reasons identified in this study as to why health providers might not get complete patient histories when working with Afghan immigrant women: (a) hesitation to share sensitive issues; (b) fear of what the Canadian social system will do with that information; (c) language differences; (d) the use of interpreters; and (e) trust.

**6.1.1.1. Sensitive issues.** M. expressed that it can be difficult for Afghan immigrant women patients to share sensitive issues relating to their family life or personal life. One reason why sensitive issues may not be shared relates to cultural norms. For example, issues involving family conflict are kept hidden:



Let's say a family, (.) a husband is beating up the, the wife. It's really hard, yes? She has bruises everywhere. And she's not happy with this guy. She cannot divorce. (.) or, yes? Because of culture and families and (.) and all kind of things. And, and she keeps everything inside. (Rasa)

Traditional Afghan immigrant women who struggle with depression and anxiety may also avoid expressing their conditions because they are afraid of accusations: (a) that they are on drugs, (b) that they are crazy, (c) that they are in love, or (d) that they are not happy with their husbands (Lisa, M., Rasa). Finally, they may not be comfortable with sharing gynecological issues with male doctors: "[They] are afraid to go to a male doctor in case, they have some other sort of chronic pain that may involve, some privacy aspects." (Lisa)

**6.1.1.2. Fear of the system.** The second reason that the real story might not be shared with healthcare professionals involves Afghan immigrant women's fear of what the Canadian social system might do with that information:

Hitting your child back home is a normal thing. And then, so, or just kind of having this domestic, you know, tension, is common. When it's recognized, you know that, (we may lose) the child, that might be hidden. So, you could have a patient who comes in with chronic pain but, what's the cause of the chronic pain if they're not telling you that they don't have a good relationship with the husband, who's hitting them (.) because they don't want to lose their children. (M.)

**6.1.1.3. Language differences.** The third reason that health providers may not get the real story is because of language differences. Because of difficulty with communication, patients may share less in Canada than they would in Afghanistan: "[In Afghanistan] when they see a doctor maybe they will say okay I need this or I need that, and, and this. So maybe here they might say... they might keep it, (half) with themselves" (Rasa). Lisa said that communication barriers caused by language differences are frustrating for both patients and health providers: "There is a huge language barrier for some people with the healthcare professionals and I think that can leave both parties really frustrated because they can't communicate." (Lisa)

**6.1.1.4. Interpreters.** Health providers may use interpreters in an attempt to solve language barriers with Afghan immigrant women. However, communicating through an

interpreter is often challenging. First, information may be lost in the process of three-way communication:

You know that, if two people talk together, it's much more easier than talking to three people that what I told you you... tell her or tell him, and (.) by the time it gets to the last person there will be nothing left. (Rasa)

Second, the interpreter may not be able to understand and translate everything that is said: "To be, a good interpreter, it's also hard, for, people... most of the time for medical terms that they are using... for somebody (.) who just speak a little English, it will be very hard." (Rasa)

Finally, communicating sensitive issues may be restricted if the interpreter and patient know each other:

Translators come in, but, what you need to remember is that sometimes they bring in family members and, I would question the accuracy of that. Both in terms of, just the problems that I mean, even in Canada people have issues, discussing sensitive issues. So then, is the patient actually expressing those issues to the translator, or is the translator actually accurately, telling you that? (M.)

**6.1.1.5. Trust.** In Afghanistan, not all Afghan women trusted the healthcare system "because healthcare somehow was affiliated with government and, you couldn't say certain things." (M.) Furthermore, the healthcare system in Afghanistan did not establish patient confidentiality. Without confidentiality, people had to hide from healthcare professionals the problems that might bring shame to the family:

Even with the doctors and maybe those people, because of the culture (.) and the shame. And the (.) what they called it? Family, the honor and dignity and all those kind of things. They are not sharing those issues. I'm sure that these things are happening (.) It's kind of (.) here, everything is open, but there everything is kind of hide. (Rasa)

M. and R. both discussed the importance of establishing a trusting relationship between Afghan immigrant patients and their healthcare professionals. M. described it as a challenge: "The challenge first I think would be establishing a good, and trusting relationship with them." R. agreed that trust is an important but very difficult issue when working with Afghan patients, attributing it in part to Afghanistan's history. In R.'s

experience, developing trust took a lot of time with patients from Afghanistan. Speaking about the successful development of trust with one of his clients, R. added, “That was after at least a year of working together of course.”

**6.1.2. Perspectives on pain management.** Sometimes, Afghan immigrant women’s perspectives on pain management are different than the Canadian healthcare system’s perspectives. These differences in perspectives are based on cultural differences and/or levels of education. Miscommunication caused by perspective differences can lead to poor adherence to treatment strategies and may harm patient –health provider relationships.

Patients and health providers may have different cultural perspectives regarding what their role is in pain management (for more on the Afghan women cultural model of pain management, see Chapter 5). Some patients who seek a cure demonstrate poor adherence to treatment strategies that involve active participation and lifestyle changes. They may expect treatment to be short with quick relief, and they may disagree with the prescribed treatment strategies:

... Let’s say you have chronic back pain and you weigh 350 pounds and your doctor says okay you need to do stretches every few hours. Often times there, there isn’t that activity being done just because, they’re afraid of making the pain worse or they, just don’t agree with the method that the doctor is using to deal with the pain. They think that rest will make it better. (Lisa)

Patients who don’t understand the reasons for different treatment strategies may demonstrate poor adherence with treatment strategies and may be dissatisfied with the healthcare interaction. (Lisa, M.) M. said, “Do they understand what the cause of the pain is?... They might be just thinking that it’s, one component and, the healthcare provider’s not doing anything.” (M.) This may lead to poor management of pain symptoms:

Individuals who have had pain and are, you know directed by their doctors to change certain lifestyle things to, try and manage their pain they don’t often do it. They don’t really understand the purpose of the treatment, and, the reason or the cause of that pain. They just see it as “Oh it will pass” or “Oh I’m doomed I’m just getting old and this is what happens.” (Lisa)

**6.1.2.1. Self-efficacy.** Maddux (2002) defined self-efficacy as a person's beliefs about his or her ability to coordinate skills and "attain desired goals in particular domains and circumstances" (p. 278). Ajzen (2002) defined self-efficacy as a person's perceived capability to control his or her own functioning and the events that impact his or her life. The term *functioning* is a broad term that includes caring for one's own body and one's health (including pain). A number of factors that influence self-efficacy among Afghan immigrant women may also influence their ability to manage their pain:

1. The Afghan women cultural model of pain influences self-efficacy because the model reflects the paternalistic healthcare system in Afghanistan, where "the doctor makes you better" (R.). The responsibility for healing is in the hands of the healthcare professional (Lisa, M.). Culturally, Afghan women "don't make their own goals. So then they're expecting an outcome based on what you [as the healthcare professional] do" (M.). This can lead to poor outcomes if they are seeking help within the Canada healthcare system. For example, M. said: "if you have diabetes... you need to exercise you need to eat well. But if you're not making that, cultural aspect change, in order to meet, your goal... [your health is unchanged and] how is the doctor supposed to do anything?" (M.)
2. Family dynamics influence self-efficacy because Afghan families are interdependent (M.). An Afghan woman's husband, parents, or other relatives may make decisions for her (Zahra, M.). Furthermore, in Afghan culture, women play a very important role in the home. They are expected to sacrifice their lives for their families: "Once you have a family, it's almost you're sacrificing everything because you're busy, you know, providing for your family whether you're working outside or even inside the house" (M.). Depending on their family relationships, Afghan immigrant women may or not have relief from their family duties in order to manage their pain. Rasa said, "Health is important for everybody, and for Afghan women so they have to be healthy all the time to work for everybody at home." Some husbands may expect their wives to maintain their regular duties regardless of their pain (Lisa, Rasa, Zahra). They may not be given time for their own health, because they are expected to put the family's needs above their own (M.).

3. Religious views influence self-efficacy because many Afghans have fatalistic beliefs. Coming from an Islamic heritage, they believe that Allah (God) controls all things. If they believe that their pain is a form of punishment from Allah, they may think that they have no control over their situation (Lisa, R.). This may hinder their efforts to seek help.
4. Past experiences influence self-efficacy because Afghanistan has spent many decades in turmoil as a result of ongoing warfare. Many women who lived in Afghanistan felt that they had no control over their situations or their lives (R., Sheila). They may continue to feel this way, thus hindering their ability to make positive changes to manage their pain.

As demonstrated, self-efficacy may have a strong impact on the ability of Afghan immigrant women to manage their pain. For some women, having low self-efficacy has been a barrier to healthcare access and pain management.

**6.1.3. Summary.** As Afghan immigrant women access the healthcare system, they encounter various barriers to managing their health. The two main barriers included in this chapter are communication difficulties between Afghan immigrant women and healthcare professionals and their differing perspectives on how to manage pain. Communications between healthcare professionals and Afghan immigrant women are made difficult because Afghan women may hesitate to share sensitive issues, fear what the Canadian social system may do with the information that they share, encounter language difficulties, and mistrust their healthcare professional. Different perspectives on how to manage pain may prevent Afghan immigrant women from using treatment strategies that are outside of their cultural model (see Chapter 5, Cultural Model of Pain Management). If they interpret the cause(s) of their pain differently than their healthcare professionals (see Chapter 5, Cultural Model of Pain Experience), they may not believe that the healthcare professional is addressing the problem. If they do not understand, within their cultural framework, the treatment strategies that are prescribed, they may become noncompliant and dissatisfied. Finally, perceived low self-efficacy regarding their ability to manage their pain may be a barrier to healthcare access and pain management.

## Chapter 7

### Discussion

This chapter begins with a summary of the findings identified in Chapter 4 through 6. This is followed by a discussion of the significance of findings in the context of pain literature and clinical practice. Then, the limitations and strengths of this study are discussed. Finally, I address potential future directions for research that are identified as a result of this study.

#### 7.1. Summary of Findings

In this study, data from SF-36 Health Surveys suggested that the physical health of Afghan immigrant women may be better than their mental health (see Chapter 4). Culturally, Afghan immigrant women experience and manage their chronic pain holistically across multiple factors: environmental, spiritual, biological, and psychological (see Chapter 5, Summary of Cultural Model of Pain Experience and Summary of Cultural Model of Pain Management). When Afghan women experienced and managed their pain on an individual level, they conformed to or differed from their cultural model in varying amounts. Finally, different cultural perspectives on pain experience and management, as well as communication difficulties with healthcare professionals, are barriers in healthcare access that prevent Afghan immigrant women from managing their pain well (see Chapter 6).

#### 7.2. Significance of Findings in the Context of Literature

**7.2.1. Cultural model of pain.** A cultural model of pain, as constructed in Chapter 5, is a set of ideas, beliefs, meanings and practices that a cultural community has developed around pain. Constructing a cultural model of pain contributes to this study because “language and culture play some role in the phenomenon of pain” (Fabrega, 1989, p. 235) and also because “culture is a key factor in pain process” (Pugh, 1991, p. 19). How people view pain culturally will influence the way that they interpret the meaning of their pain, the way that they express their pain, and the way that they manage their pain (Pugh, 1991; Solomon, 2001; Callister, 2003; Von Baeyer & Spagrud, 2006; Grilo, Treves, Preux, Vergne-Salle, & Bertin, 2007).

The cultural model of pain in Chapter 5 was constructed from two sources: the literature and interview participants. The following sections present the literature that is available on the Afghan cultural model of pain experience and the Afghan cultural model of pain management. As demonstrated in Tables 2 and 3, the literature and interviews complemented and supplemented each other in constructing the cultural model of pain.

**7.2.1.1. Cultural model of pain experience.** According to the literature, the Afghan community may attribute multiple factors to their pain experience:

1. *Environmental factors (including social and physical environments)* - Afghan people believe that environmental factors, such as isolation, can cause physical pain. For example, Aziz (1999) said, “they perceive their increased sense of isolation and loneliness as negative aspects of life and reflect these problems in bodily illness, pain, and depression” (p. 221).
2. *Spiritual factors* - Afghan people believe that spiritual factors such as *Nazar* (the evil eye), *jin* (evil spirits), or punishment from Allah (the Muslim and Arabic word for God; Thompson, 1992), can cause physical pain (Pugh, 1991; Aziz, 1999). The evil eye, or *Nazar*, is when someone looks at another with bad thoughts or intent. If sudden harm or illness comes to a person who is doing well, it is believed that the evil eye may be a cause for the harm or illness. (Aziz, 1999). Evil spirits, or *jin*, can cause many physical ailments such as bruises, broken bones, and headaches. They believe that *jin* affect women and children more than men, as women and children are thought to be weaker than men (Aziz, 1999).
3. *Psychological factors* – Afghan women experience *somatization* as a consequence of depression, anxiety, and PTSD (Kleinman & Good, 1985; Aziz, 1999; Aziz, 2011).

**7.2.1.1.1. Somatization vs. holistic experience.** Somatization, identified commonly among individuals with psychosocial distress (Tavafian, Gregory, & Montazeri, 2008), is “a process whereby a mental event is expressed in a body disorder or physical symptom” (Mosby’s Pocket Dictionary, 2002). Furthermore, a somatization disorder is a “psychiatric disorder characterized by recurrent multiple physical complaints and symptoms for which there is no organic cause.... The symptoms vary according to the individual and the underlying emotional conflict” (Mosby’s Pocket Dictionary, 2002). Afghan immigrant women experience

somatization: “I think there is an underlying, connection with the emotional distress that they [Afghan women] are in, and perhaps their bodies are physically trying to tell them that they are going through emotional distress.” (Lisa)

The use of the terms *somatization* and *somatization disorder* are from Western culture; separating pain in somatic/organic versus emotional categories is a Western cultural phenomenon (see *Figure 2*). Not all cultures view the mind and body separately. For example, according to Erna Hoch, patients from India did not distinguish between physical and emotional attributes of pain. The relationship between physical and emotional pain was causative bi-directionally: “Physical pain in Indian culture incorporates psychological malaise, while emotional distress manifests itself simultaneously in both mind and body.” (Pugh, 1991, p. 26) Similarly, women from Turkish folk-culture discussed the emotional aspects of their illness using terms that relate to their body and organs (Devisch & Gailly, 1985).

Because somatization does not fit within Afghan cultural perspectives (see *Figure 2B*), it seems incongruous to use it within the framework of the Afghan cultural model of pain. Therefore, in Chapter 5 *holistic experience* is used instead of *somatization* (see Holistic Experience). Viewing this phenomenon as holistic experience rather than somatization may lead to different interpretations of what is happening. In the following paragraph, I demonstrate how these different perspectives may influence the interpretation of emotional pain that is expressed somatically.

Kleinman & Good (1985) reported that non-Westerners tend to emphasize their somatic symptoms and downplay their mental/emotional symptoms (p. 286), and that many non-Western societies express their mental illness through somatization (p. 433). These findings are interpreted through Kleinman & Good’s Western cultural perspectives in which factors of pain are more distinctly categorized (i.e., physical pain vs. emotional pain). Instead, I suggest viewing pain experiences on a continuum from forming distinct categories of pain (i.e., emotional pain vs. physical pain) to more holistic experience of pain (see *Figure 2* in Chapter 5). From this “continuum” perspective of pain experience, Kleinman & Good’s (1985) findings would be interpreted as a more holistic experience of pain, and one would therefore expect emotional pain and physical pain to be expressed in unity, not separately. The findings from this perspective would not be that non-Westerners emphasize vs. downplay the physical and



emotional aspects of their pain experience (respectively), but rather that they experience different aspects of their pain cohesively, as one.

**7.2.1.2. Cultural model of pain management.** In the literature, Afghan women believe that spiritual practices are important for pain management. Their prayers and religious rituals include methods to ward off the evil eye and methods to remove *jin*. They also seek cures through religious leaders, including mullahs, and saints (Aziz, 1999; Aziz, 2011). Pain acceptance is another faith-based way that they manage pain, as many Muslims are fatalistic and believe that anything that happens in life is Allah's Will (Aziz, 1999). Religious leaders will often advise a woman to have patience, which is a virtue that is well known among Afghan women. "It is believed that through patience one's pain dissipates and God rewards with eternal comfort." (Aziz, 2011, p. 237)

Pain management for Afghan women also includes cultural remedies and access to the healthcare system (Lipson et al., 1995; Omeri et al., 2006). When encountering the healthcare system, Afghan women expect that the healthcare professional will cure or alleviate their problems. They are more likely to think that treatment should be short with quick relief (Aziz, 1999). Pain management strategies include rest and taking medications (Keefe & Smith, 2002). Afghan women focus on their somatic complaints; therefore, they expect treatment to primarily concentrate on their physical symptoms (Aziz, 1999).

**7.2.2. Pain as multifactorial.** In the literature, pain could be considered multifactorial because multiple agents, or factors, are described to contribute to pain experience. The experience of pain is complex:

[Pain] depends on a host of variables, including the presence of other somatic stimuli and psychological factors such as arousal, attention and expectation. These psychological factors in turn are influenced by contextual cues that establish the significance of the stimulus and help determine appropriate responses to it. For example, traumatic injuries sustained during athletic competitions or combat are often initially reported as being relatively painless, although these same injuries would probably be extremely painful under other circumstances. (McMahon & Koltzenburg, 2006, p. 125)

In pain experience, the central nervous system (CNS) interacts with level of arousal, expectation, and attention to produce subjective, neural, and behavioral pain responses (McMahon & Koltzenburg, 2006). The CNS is also influenced by (1) biological processes, such as inflammation and infection; (2) psychosocial factors, such as emotions, depression, and anxiety; (3) environment, such as a person's learned associations between the environment and pain, or threat; and (4) cognition, such as a person's beliefs regarding his or her ability to manage pain (Bradley et al., 2002).

In the literature, a model that includes biological, psychological, and social factors (the biopsychosocial model) is commonly used (Borrell-Carrio, Suchman, & Epstein, 2004). The biopsychosocial model was not used for this study's constructed cultural model of pain because it does not adequately describe pain experience for Afghan immigrant women; it does not incorporate spiritual and environmental factors. For this study, pain attributions are categorized into one or more of four factors: biological, psychological, spiritual, and environmental (including social and physical environments).

This study supports the literature in viewing chronic pain as multifactorial (see Chapter 5, Cultural Model of Pain Experience). However, to my knowledge the literature recognizes that multiple factors, such as social environment, *contribute* to somatic pain experience, but not that they *cause* somatic pain. In this study, multiple women reported that their physical pain was not only influenced by, but also caused by environmental factors. The following section on acculturation emphasizes the importance of environmental factors in pain experience for Afghan immigrant women.

**7.2.2.1. Acculturation as an example.** In this study, acculturation was mentioned as one of the attributed causes of pain for older women. The term *acculturation* is “a process that is *executed by* an agentic individual [italics added]... after meeting and encountering a cultural community that is different from the cultural community where he or she was initially socialized.” (Chirkov, 2009, p. 106). Acculturation is dynamic, and varies from community to community and from individual to individual. Influences of acculturation include gender, time since immigration, social environment, age at immigration, and reason for immigration (McDermott-Levy, 2009).

Lisa expressed that, in moving to Canada, the older generation does not understand the acculturation of younger Afghan immigrants. Lisa, as a part of the younger generation, said:

They didn't think you know, they're going to be going to school with, children who are going to influence them, you know, extremely on, on a level far beyond than what a parent can do even. And they're going to interact with individuals who are going to, bring about new thoughts and new ideas to them.... We come from such a traditional culture that, change is seen as a bad thing but, you can still experience change in some aspects and be able to stay true to yourself and I think, they have a hard time with that.

Acculturation was a source of pain for older women in this study: "When your kids get adapted to this culture but you want to raise them according to that culture.... that, kind of causes pain. Maybe not in younger people, but like, parents." (M.) One reason that the acculturation process was so difficult for parents was because, as children acculturate, they (the children) may reject values that are important to Afghan culture. Rasa said:

Most of my concerns are my children... they are changing. Which is, you see. It's hard. You cannot hold somebody not to change, you know. "Hey, you, who you are? You came from somewhere, else. You don't have to change. You cannot change." It's really hard you cannot do that. Because they are (.) in this community, in this country, you know.... They are losing the values.

The effects of acculturation on somatic pain are worth further exploration. More research is also needed to understand the effects of psychological and environmental factors (including social and physical environments) on pain experience, as well as potential applications of this information in the context of health promotion.

**7.2.3. Barriers to pain management.** In Chapter 6, I identified four reasons for communication difficulties between healthcare professionals and Afghan immigrant women patients: sensitive issues, fear of the social system, language difficulties, and trust. The literature presented here highlights two of these four reasons: sensitive issues and trust. As Chapter 6 also identified perspectives that can contribute to poor pain management, this section concludes with a discussion of literature that is available on the relationship between self-efficacy and health.

**7.2.3.1 Sensitive issues.** According to the literature, Afghan women may not access the healthcare system because sharing of family or personal information with others is discouraged (Brodsky & Faryal, 2006). They are afraid of "gossip, losing face, or sharing sensitive personal

information, such as nearly anything about the family' (Lipson & Omidian, p. 274)" (Aziz, 1999, p. 90).

**7.2.3.2. Trust.** Aziz (1999) agreed that developing trust in the clinical setting is difficult but important: "Among Afghans, trust generally does not extend beyond family and close friends or to outside institutions" (p. 120). Brodsky & Faryal (2006) attribute their wariness of outsiders to Afghanistan's long history of political unrest. Afghan communities have been, in some places, closed off to outsiders, including other Afghan immigrants that were not family members or close friends. According to Aziz (1999), "most elderly women are distrustful and fear that any information they give will be used against them" (p. 232).

**7.2.3.3. Self-efficacy.** According to Kleinman & Good (1985), level of efficacy, or feelings of one's own control over outcomes, can have a strong influence on outcomes. Those who have high self-efficacy are better able to cope and adapt, whereas those who have lower self-efficacy tend to use "blunting" or distracting activities to cope (such as food or drug addictions). Lower self-efficacy may also lead to higher levels of somatization, withdrawal, and feelings of helplessness (p. 253).

In this study, I demonstrated how self-efficacy might influence Afghan immigrant women's ability to manage pain (see Chapter 6, Self-efficacy). This study does not link low self-efficacy with addictive behaviors. However, each of the four examples in Chapter 6 demonstrates a negative impact of low self-efficacy on Afghan immigrant women's ability to access healthcare and manage pain. More research is needed to understand the effects of self-efficacy on the lives of Afghan immigrant women.

## **7.3. Clinical Implications**

**7.3.1. Pain as multifactorial.** As outlined in the previous section, the holistic, multifactorial pain experiences of Afghan immigrant women support current pain literature. These findings are also significant in the context of clinical practice. This section starts by discussing the importance of treating pain holistically across multiple factors, presented in the context of disease vs. illness. Then, the application of holistic care is applied to physiotherapy practice.

**7.3.1.1. Disease vs. illness.** The definition of *disease* is "a condition of abnormal vital function involving any structure, part, or system of an organism", whereas *illness* is defined as

“an abnormal process in which aspects of the social, physical, emotional, or intellectual condition and function of a person are diminished or impaired, compared with that person’s previous condition” (Mosby’s Pocket Dictionary, 2002). Disease emphasizes the biological factor of sickness, whereas illness represents health more holistically across multiple factors. This quote, written by Good in 1977, remains true today: “The ‘medical model’, which conceives diseases as natural entities that are reducible to physiological terms and are essentially free of cultural context, continues to have great force” (p. 26).

The importance of considering both disease and illness in health settings was emphasized decades ago by Kleinman, Eisenberg, & Good (1978). However, Western healthcare settings have a history of emphasizing the biological aspects of illness as being the “real” ones (Kleinman, 1980, p. 57). Even today, healthcare professionals view patients with psychosomatic and psychosocial problems as “difficult”, whereas patients with biomedical problems are considered the “good” patients (Foster & Delitto, 2011, p. 793). To illustrate, one participant in this study shared a conversation she had heard about, which occurred between a doctor and husband. She said, “He [the doctor] said... ‘I’m not touching this lady. She has depression. She has no health issues.’ The husband got upset and, he said that ‘No, she is sick. She’s physically sick.’... So the doctor said, ‘You know, if you don’t accept what I’m saying, the reality... come back after 14 years. She will be worse, and she will have the same symptoms.’” In this story, the doctor’s perspectives reinforced biomedical views of sickness and did nothing to promote psychosocial health for the woman or her family.

**7.3.1.2. *Physiotherapy practice.*** Although biopsychosocial models are used in today’s clinical settings, the majority of physiotherapists’ time and energy are still spent on biomedical assessment and treatment. Physiotherapists and other healthcare professionals use primarily biomedical perspectives to explain and treat pain, but doing so may lead to poor patient outcomes; it reinforces notions that patients have anatomical links to their pain and disability. It may also lead to focusing on symptoms of pain while overlooking important psychosocial factors (Foster & Delitto, 2011; Nicolas & George, 2011).

Part of the problem, according to Linton & Shaw (2011), is the deficiency of guidelines for applying biopsychosocial knowledge of pain into the clinical setting. In applying biopsychosocial knowledge, Linton & Shaw suggested emphasizing function when setting goals with patients. However, in the context of the Afghan cultural model of pain management, (see

Chapter 5, Summary of Cultural Model of Pain Management), this suggestion may be difficult to implement among Afghan immigrant women. Those women who embrace the cultural model of pain management may not understand this treatment strategy because their cultural strategies for pain management include rest and seeking a cure; they may not expect to actively participate in treatment (see also Chapter 6, Perspectives on Pain Management). Therefore, if a physiotherapist attempts to emphasize function and incorporate patient goal setting in pain treatment strategies for Afghan immigrant women, clear two-way communication and patient conviction concerning the treatment strategies will be very important.

In order to incorporate psychological and social aspects of pain into physiotherapy practice, Linton & Shaw (2011) also suggested including (mental) distraction techniques, education, relaxation techniques, and graded activity training in pain treatment plans. French (1989) suggested reducing anxiety by giving patients control, giving patients information if they seek it, and being consistent (e.g., being consistent with the environment in which they meet, healthcare provider to patient interactions, and choice of treatment strategies). If Afghan immigrant women internalize their cultural model, giving them control and giving them information may not be appropriate treatment strategies (see Chapter 6, Perspectives on Pain Management). However, giving Afghan immigrant women some level of consistency might contribute to their pain management by lowering their levels of anxiety. For example, they may benefit from having consistency in seeing the same healthcare professional from one visit to the next, rather than seeing whoever else may be available.

**7.3.2. Cultural competence.** Sometimes, in the healthcare setting, the phrase *cultural competence* is limited to overcoming language barriers with patients. However, as the last section demonstrates, cultural competence is much broader than this, and includes an ability to understand and incorporate cultural perspectives. Cultural competence also includes an understanding of possible cultural differences in level of family involvement, level of autonomy, or disclosure of information (Oliffe, Thorne, Hislop, & Armstrong, 2007), and the understanding that health and illness are culturally defined (Kleinman & Good, 1985).

Lofvander et al. (2004) explained that, although physical exercise and cognitive support are perhaps the most effective treatments available for benign chronic low back pain, treatment strategies need to align with immigrant populations' belief systems, knowledge, and cultural traditions. Similarly, Aziz (1999) recommended that healthcare professionals should work

within Afghan immigrant women's belief systems rather than confronting them. It may be difficult to know what their belief systems are, because Afghan refugee communities are diverse in class, ethnicity, political views, culture, and region, whether of urban or rural origin (Lipson, 1991; Aziz, 1999). Cultural integration of Afghan immigrant communities into their host countries also varies (Aziz, 1999). Therefore, in the pursuit of cultural competence, healthcare professionals must be careful to avoid stereotyping their Afghan immigrant patients.

**7.3.2.1. Avoiding stereotypes.** As Chapter 5 demonstrated, Afghan immigrant women's perspectives may conform to or differ from their cultural model of pain in varying amounts; their experiences and management of pain also differs. The information from this study, in formulating cultural norms, is intended to create a framework rather than a set of rules for working with Afghan immigrant women. Culturally competent care will always consider individual characteristics: "Individual differences exist within cultural groups; thus, the pain experience should be understood within the context of patients' beliefs, values, coping strategies, and life experiences." (Callister, 2003, p. 210)

**7.3.2.2. Truth telling.** Informed consent is an important component of healthcare access in Canada. However, informed consent needs to be provided in a culturally sensitive way. "Many non-Western cultures prefer less information and do not desire full disclosure." (Oliffe, Thorne, Hislop, & Armstrong, 2007, p. 11) They view bad news as a more delicate matter, and present it in a more subtle way than we do in Canada. Oliffe et al. (2007) described a Persian woman who sadly recalled the information she received concerning potential chemotherapy side effects. Although she recognized that the information was well intended, it "left her feeling hopeless. She recalled that the nurse 'wanted to prepare me for this' but she said that 'too directly giving information can crush the spirit.'" (p. 8)

Besides psychological distress, providing medical information to patients without considering their cultural background may also impact their quality of life in other ways. Rasa shared a story of a man who had terminal illness. It was culturally inadvisable to tell the sick man of his prognosis: "in our country we don't tell directly to the person" (Rasa). However, in this example the healthcare professional insisted that the patient needed to know. As a result, family relationships and customary end of life care were negatively impacted for this man and his family.

Although disclosure of information is identified as a potential barrier to culturally competent care for Afghan immigrants, this study does not identify any culturally sensitive ways to deal with information disclosure in clinical settings. Informed consent and information disclosure are included in healthcare policies and reflect Canadian cultural values. More research is needed to explore how to implement of these policies across cultures and how to disclose information in culturally competent ways.

**7.3.2.3. Professional Conduct.** A few reflections on appropriate professional conduct for interactions with Afghan immigrant women are discussed here, although professional conduct was not explored extensively in this study. Healthcare professionals may need to refine their definition of professional conduct when working with Afghan immigrant women. Once a traditional Afghan immigrant woman trusts her health provider, she may view him or her as she would a family member or friend (Aziz, 1999; R.). For example, an older Afghan woman who has grown to trust her female healthcare professional may expect close physical distance (about 2 to 3 feet) and touch, as frequent touching signifies closeness and comfortableness. Although the female healthcare professional may not initiate this type of contact, backing away from these gestures of acceptance may insult the older Afghan woman. Furthermore, offering food is an Afghan gesture of acceptance; if a woman offers food, refusing to accept is interpreted as disrespect or rejection (Aziz, 1999).

**7.3.2.4. Sharing pain.** As discussed in Chapter 5, sharing pain experiences and treatment ideas is an important management strategy for many Afghan immigrant women. In this study, it seemed that at least two participants valued the opportunity to share their pain experiences and treatment ideas with me. In healthcare settings, brief interactions and unwelcoming environments may prevent Afghan immigrant women from receiving this aspect of culturally competent care. This is a challenging dilemma, because time limitations and staffing shortages are indisputable problems that healthcare professionals and patients face. However, knowing that sharing pain is an important aspect of pain management for many Afghan immigrant women should encourage female healthcare professionals to support Afghan women's efforts to share pain. This is a part of culturally competent care for some Afghan immigrant women, and may also help to build a stronger patient-health provider relationship.

**7.3.2.5. Religious practices.** Religious practices may have an interesting effect on the health of Afghan immigrant women. For example, Ramadan, the Muslim month of fasting, had



tremendous effects on one participant in this study. Although she could usually do most housework herself, she required assistance with all household tasks after fasting for the month of Ramadan. As the SF-36 asks many questions that relate to the last 4 weeks, being aware of time in relation to the month of Ramadan may be relevant information to note if the participant is fasting. Beyond the use of the SF-36, being aware of time in relation to Ramadan may be helpful in the healthcare setting when interacting with an Afghan immigrant. A physiotherapist, for example, might consider the effects of fasting on energy levels, because Muslims who follow strict fasting procedures during the month of Ramadan will neither eat nor drink during daylight hours.

**7.3.3. Overcoming barriers in healthcare access.** Chapter 6 identifies barriers to pain management, from this study, in the context of Afghan immigrant women accessing the healthcare system. This section includes a discussion of some ways to overcome these barriers in the clinical setting.

**7.3.3.1. Communication and education.** Clear communication and education are very important tools in healthcare interactions. The perspective differences that may exist between healthcare professionals and Afghan immigrant women make implementing clear communication and education even more important. Among other things, clear communication and education may include interactions in which healthcare professionals and Afghan immigrant women educate each other about what roles they expect each other to play and what outcomes they expect from the interaction. These interactions need to be two-sided:

I believe it's both sides, you know? It's not only the healthcare providers. People also have to be open and share.... But if you, have expectation from the healthcare providers, you only know about yourself, about your culture. (But) how can they learn about one hundred cultures and so many languages? What do you want, what is your expectation? You also have to be open to share, who you are, and what is your expectation. (Rasa)

Healthcare professionals can promote this type of communication with their patients by asking questions and by demonstrating flexibility when patients express their expectations.

Although direct communication between the health provider and patient is preferred, interpreters are often needed because of language barriers. When using an interpreter, M.

recommended that interpreters should not be family members or friends of the patient. She believed that this may help in situations where the patient has sensitive issues to discuss. In the literature, Aziz (1999) agreed that, if possible, the translator should not be a relative. Aziz also recommended using a translator from the same ethnicity and gender (i.e., an Afghan female). Finally, young children should not be translators because of the authority and power differences between women and children (Aziz, 1999).

Clear communication may take more time when working with Afghan immigrant women because of language and cultural barriers. However, without clear communication and understanding, adherence to treatment strategies as well as patient-health provider relationships will suffer. Consequently, and more importantly, patients' abilities to manage their pain may be restricted.

**7.3.3.2. Family roles.** Another important consideration in planning treatment strategies for Afghan immigrant women is their role at home. Lipson & Miller (1994) explained, "extended family obligations, especially to parents and older siblings, often supersede other responsibilities... certainly to one's own needs" (p. 174). M. agreed: "Regardless of how old you are, even if you're 30, especially if you're a woman, you should not make, you should not have schedules... that is supposed to (meet) your kind of needs, your wants." It may help healthcare professionals to learn what patients' family roles are and what treatment strategies may or not work for them within their family context. Because Afghan immigrant women are expected to put family needs above their own, encouraging them to care for their own health may be a process (M.).

**7.3.4. Faces Pain Scale – Revised.** The Faces Pain Scale – Revised (FPS –R) was designed for pediatric populations, although it has been used successfully with adult populations who have cross-cultural language barriers (Li, Liu, & Herr, 2007). In this study, difficulties were encountered in using the FPS-R with at least 2 adult participants. Both of these participants misinterpreted the meaning of the faces represented on the FPS-R. Instead of using the FPS-R to represent how they felt about their pain, they used the faces to represent the facial expressions they would use when they have pain. This is an important distinction, as adults will sometimes suppress the expression of pain based on social or cultural norms. When Jane saw the FPS-R she said, "Even when I have pain, I don't show it on my face. I always smile." Clarification was needed before she was able to use the FPS-R correctly. Similarly, Herose first pointed to the

face on the FPS-R that represents 0/10, saying, “This one, I try to smile some.” However, when asked if that was how she felt inside, she pointed to the face representing a pain intensity of 4/10.

The FPS-R was designed for pediatric populations. In pediatric populations, the difficulty encountered in this study may be less problematic because children are less likely to mask pain expression. Instructions for the FPS-R advise: “Point to the face that shows how much you hurt [right now].” The form includes a statement that the “scale is intended to measure how children feel inside, not how their face looks” (Hicks, von Baeyer, Spafford, van Korlaar, & Goodenough, 2001). When using the FPS-R with adult populations, it may help to clarify this, saying something such as “Point to the face that shows how you feel inside, not how your face looks.” However, more research is needed to determine the validity and reliability of using the FPS-R with adult populations.

## **7.4. Limitations and Strengths**

**7.4.1. Limitations.** This study has a number of limitations. These limitations relate to recruitment difficulties, questionnaire forms, participants’ levels of literacy and education, English and Farsi translations of questionnaires, communication difficulties, and available resources. The limitations of this study are presented next using this order.

**7.4.1.1. Recruitment difficulties.** Multiple amendments and revisions were made to this thesis because of low participation (see Chapter 3 to review amendments and revisions). A number of possible reasons for low participation in this study are addressed here and in the following sections of this thesis. Recruitment difficulties may have been influenced by mistrust, as developing trust takes a lot of time with this population (see Chapter 6, Trust). Recruitment difficulties may have also been influenced by cultural preferences in the study design, as Afghan immigrant women prefer personal contact rather than questionnaires (Part 1). Finally, recruitment difficulties may have been influenced by communication difficulties with potential participants.

This study was constructed with very little knowledge of the cultural preferences of Afghan immigrant women. Not implementing their cultural preferences into the structure of this study may have led to lower levels of participation. For example, Part 1 was structured so that participants could take questionnaire packages home with them and fill them out as they had

time. The intent was to maximize participation by minimizing the effect that this study would have on participants' routines. However, doing so may have eliminated a reason for participation – an opportunity to visit. Visiting other women is a very important and valued aspect of life for most Afghan women. Therefore, trying to maximize efficiency for these women was thinking within a Canadian cultural framework, not an Afghan cultural framework. This may have contributed to recruitment difficulties.

**7.4.1.2. Use of printed materials.** The use of questionnaires and other printed materials in this study may have been a cultural barrier to participation. Near the beginning of the study, a community member said that her community is not a “pen and paper” people. This study supports that claim through the difficulty I experienced with recruitment as well as personal experiences with participants as they completed forms.

**7.4.1.2.1. Levels of literacy and education.** Three women who participated in this study were unable to write in English or Farsi. To fill out forms, they either required assistance from a family member or an ability to understand and speak English with me. One participant was able to read the Farsi consent form but unable to fill out forms. Her family member remarked that she had never filled out a form before; her ability to read, then, did not equate to an ability to fill out forms.

In this study, the median years of education was 15 years. It is possible that, by using questionnaire forms, this study selected for participants who had higher levels of education. Therefore, to recruit participants more equally across levels of education, future research with this population should consider eliminating reading or writing requirements.

**7.4.1.2.2. English and Farsi translations.** Two questionnaires used in this study have been translated from English into Iranian Farsi. As Iranian Farsi is similar to Afghan Farsi, we (community members and I) expected no difficulty in using the Iranian translations of the SF-36 and the SF-MPQ with Afghan immigrant women. However, the I-SF-MPQ has at least one affective descriptor, *sickening*, that Rasa said was different in Iranian Farsi compared to Afghan Farsi. It is not known whether the other 2 participants who completed the I-SF-MPQ also had difficulty with this specific descriptor, although M. commented that she had some difficulty with the words used in the I-SF-MPQ.

**7.4.1.3. Communication difficulties.** Comprehension was a great obstacle and challenge through the course of this study. Although providing translations of the SF-36 and SF-MPQ in

Iranian Farsi enhanced comprehension levels for some women, participants would have benefited from having questionnaires available in Afghan Farsi instead. Furthermore, the recruitment process, data collection, analysis, and results were all limited by language difficulties. In recruitment, I often spoke to many family members because potential participants could not understand English. During interviews, misunderstanding the questions (as an interviewee/participant) and the answers (as an interviewer) sometimes reduced the usefulness of the exchange. For the same reason, analysis was difficult; I was unable to fully comprehend many segments of the interviews.

To demonstrate the “hazards of cross-cultural translation and (mis-)communication” (Shweder, 2008, p. 63), I use an example that I encountered in this study relating to the word *shy*. A number of times, Zahra described herself as shy. She said that although she was not happy with her doctor, she had not found a different doctor because she was shy. According to Shweder (2008), people from India use the word *shy* when they are referring to a person “who displays the emotion and virtue of respectful self-restraint and gracefully submits to the authority of others” (p. 64). Words such as *shy*, which may have multiple meanings that are dependent on cultural context, made cross-cultural communication and analysis difficult in this study.

Ideally, data from previous interviews are used to steer questions and topics in following interviews (Rubin & Rubin, 2005). However, this was difficult with some women. At times, language barriers prevented the interviews from moving to a deeper level. Furthermore, some women were interviewed in their homes with children and family members present. In these cases, the presence of family members and frequent distractions from children made communication difficult. As a result, only basic topics and questions were discussed.

**7.4.1.4. Resources.** An early plan for this study was to hire and train someone who speaks Afghan Farsi as an interviewer. This would have reduced language and communication difficulties in this study. However, resources and time were insufficient to execute this plan for this Master’s thesis. Furthermore, time limitations to complete this thesis may have resulted in premature study closure (Thorne, 2008). Study closure was based on time limitations rather than data saturation.

The literature search for articles, in developing the cultural model of pain for Afghan immigrant women, was not exhaustive. The search included three electronic databases for health

literature, supplemented by additional literature recommended by the supervisory committee. A more exhaustive literature search may have included psychology-based database(s) and word searches. As a result, relevant articles may have been missed.

**7.4.2. Strengths.** Rigorous analytical procedures are a strength of this study. Through the data collection and analysis stages of this study, a reflexive journal and reflexive memos were made in order to create a credible audit trail. Furthermore, as new data emerged, concepts from previous stages of analysis were challenged and tested (Thorne et al., 2004). Despite being unable to claim saturation, the findings from this study are based on themes that spanned interviews. Participants in this study, although few in number, spanned multiple generations and represented contrasting perspectives. The findings from this thesis are also challenged and compared to the literature (in Chapters 5 and 7). Finally, two encultured informants reviewed and approved the constructed cultural model of pain for Afghan immigrant women.

## **7.5. Future Directions**

Earlier in this chapter, I discussed the significance of this study's findings in the context of current literature. Based on these previous discussions, research is needed: (a) to advance and refine the Afghan cultural model of pain (b) to explore the attributed causes of chronic pain in non-Western vs. Western cultures; (c) to understand the effects of acculturation on chronic pain for Afghan immigrant women and other immigrant populations; (d) to understand the effects of social and psychological factors on pain experience, as well as potential applications of this information in the context of health promotion in clinical settings; (e) to understand the effects of self-efficacy on the lives of Afghan immigrant women; and (f) to explore informed consent and information disclosure in healthcare settings in the context of patients' cultural values.

**7.5.1. Physical activity norms among Afghan immigrant women.** Another area needing more research, of interest to physiotherapists, is physical activity norms among Afghan immigrant women. Although physical activity is often an important component of treatment for chronic pain and other conditions, physiotherapists and other health care professionals know very little about the cultural factors that influence Afghan immigrant women's physical activity levels.

Physical activity among Afghan immigrant women is greatly influenced by home and family dynamics. In Afghan culture, women's lives revolve around the family and their lives are

not considered to belong to just themselves. One woman described, “Life doesn’t belong to just one person. Every decision is connected to the family; we are all tied together” (Lipson & Miller, 1994). These women have often gained approval from their families and communities through self-sacrificial behavior. As a consequence, many Afghan women foster selflessness (Aziz, 1999). Therefore, participating in physical activity solely for personal health benefits is uncommon. As M. explained, “you are not to go to the gym because you’re expected to be home to cook.”

Afghan women get the majority of their physical activity from household activities. In Afghanistan, household activities kept them physically active; this included sweeping and washing floors, doing laundry by hand, cleaning heavy Persian rugs, and washing dusty walls (Rasa). In Canada, because of Canadian lifestyles, Afghan women may now live more sedentary lifestyles. However, because of cultural norms and family dynamics, it may be difficult for Afghan immigrant women to find ways to increase their activity levels in Canada. More research is needed to explore how physiotherapists and other healthcare professionals can encourage physical activity in culturally competent ways for Afghan immigrant women who experience chronic pain and other conditions.

## **7.6. Conclusion**

Cultural perspectives on pain experience and pain management influence treatment expectations and pain management. Differences in cultural perspectives are a barrier in healthcare access that prevents Afghan immigrant women from managing their pain well. Perspective differences identified in this study will increase understanding for healthcare professionals as they work together with Afghan immigrant women patients, thereby allowing them to enhance communication and overcome barriers to pain management.

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## Appendix A

### Letter of Permission to Use SF-36v2 URL



June 10, 2013

Julie Penner  
School of Physical Therapy  
St. Andrew's College, 1121 College Dr.  
Saskatoon, SK S7N 0W3

Email: [jew762@mail.usask.ca](mailto:jew762@mail.usask.ca)  
Phone: (306) 717-3821

REF: QualityMetric # CT139307/OP029144/QM019237

Dear Julie:

This letter is in response to your request, on behalf of University of Saskatchewan ("Publisher") to include OptumInsight's on-line demo URL's and survey website URL listed below (collectively, the "URL's"), in the new edition of the "Chronic Pain in Afghan Immigrant Women: An Exploratory Mixed Methods Study" ("Publication") by author Julie Penner ("Author(s)"). OptumInsight is pleased to provide the Publisher with permission to publish the **URL's**, in the appropriate chapters of the Publication as determined by the Author.

The **URL's** that can be published are as follows:

- Try a Survey website:  
<http://www.qualitymetric.com/tabid/236/Default.aspx>
- SF-36v2 Health Survey:  
[http://www.qualitymetric.com/demos/TP\\_Launch.aspx?SID=100](http://www.qualitymetric.com/demos/TP_Launch.aspx?SID=100)

The above mentioned **URL's** shall be used solely in the Author's Publication by the Publisher and for no other purpose.

Publisher will provide OptumInsight with a proof of the Publication for review, and OptumInsight retains the right to decline the permission to publish the **URL's** based on its review of the proof. Publisher will also provide OptumInsight with a copy of the final Publication in order for OptumInsight to verify that the stated requirements were met.

If the use of the **URL's** in the Publication is found acceptable by OptumInsight upon their review of the proof, OptumInsight is pleased to provide the Publisher with permission to publish the **URL's** in the Publication as depicted in the proof reviewed by OptumInsight. The Publication should also state that the **URL's** are published with permission from OptumInsight Life Sciences, Inc. (f/k/a QualityMetric Incorporated).

If you have any additional questions, please contact OptumInsight at 401-334-8800.

Sincerely,

Martha Bayliss  
VP of Operation

MB/LL



an OptumInsight company

## Appendix B

### Pain Questions Used in Part One

---

Please review the following definitions before you complete the following questions on pain.

- 
- **Pain** – An experience of hurt felt physically in one or multiple parts of your body.
  - **Chronic Pain** – Pain that has lasted for six months or greater. Chronic pain is felt every week. It may be there all the time; it may be absent on some days; or it may get worse or better based on your activities.
- 

1. Do you experience pain regularly in one or multiple areas of your body?
  - a. Yes
  - b. No

**If your response to Question 1 is No, please skip Question 2 and go to the last page (Demographic Questions).**

2. If your response to Question 1 is Yes, how long have you had this pain?
  - a. Less than 6 months
  - b. About 6 months
  - c. Greater than 6 months (please specify how many months or years) \_\_\_\_\_

## Participants with Chronic Pain

---

1. If you have had pain that has lasted for six months or greater (chronic pain), are you willing to receive an invitation to Part 2 of this research?
  - a. Yes
  - b. No

If your response to Question 1 is No, please skip Question 2 and go to the next page.

2. If your response to Question 1 is Yes, please provide your name, phone number, and/or email address

---

**Any information that identifies you will not be linked to the research results. This page will be stored separately from the rest of this survey.**

---

## Appendix C

### Demographic Questions Used in Part One

---

1. In Afghanistan, did you live primarily in a rural or urban setting?
  - a. Rural
  - b. Urban
  
2. Which language do you prefer speaking?
  - a. English
  - b. Farsi
  - c. Other (please specify) \_\_\_\_\_
  
3. Which language do you prefer reading?
  - a. English
  - b. Farsi
  - c. Other (please specify) \_\_\_\_\_
  
4. What is your current household income per year?
  - a. Less than \$10,000
  - b. \$10,000 - \$25,000
  - c. \$26,000 - \$40,000
  - d. \$41,000 - \$70,000
  - e. \$71,000 - \$100,000
  - f. More than \$100,000
  
5. How many years of education have you completed? \_\_\_\_\_
  
6. What is your age? \_\_\_\_\_
  
7. Which Afghan ethnic group do you belong to?



---

8. During which years did you live in Afghanistan? (Example: 1983-2000)

---

9. Have you spent any time as a refugee in a country other than Canada? If so, where were you and what years did you live there? (Example: Pakistan, from 2000-2003)

---

THANK YOU FOR YOUR PARTICIPATION!

Please contact Julie to pick up these forms at a time and location of your convenience.

Telephone: 966-1957

Email: [pain.research@usask.ca](mailto:pain.research@usask.ca)

## Appendix D

### Interview Guide

- How long have you had pain? (*confirm that participant has chronic pain*)
- Do you know any other women in your community who experience chronic pain?
- If so, how do you know that they have chronic pain?

Please think about this group of Afghan women as I ask you the following questions.

#### Segment 1: Cultural Model of Pain

1. In the Afghan community, how do women express their pain? Expressions might include who they tell, how they behave, their gestures, and body language.

*Cues: How can you tell if one of the women is experiencing chronic pain? Do they talk of their pain? Who do they talk to? How often? Do they wince? Frown? Limp? Rub the painful area? Withdraw from others? Do you think they try to hide their pain? Who do they try to hide it from? Are you aware of how it affects their involvement in work? Household duties? School? Child care?*

- How do people in your community respond to a woman when she expresses pain?

*Cues: ignore, offer help, etc.*

- Are there differences in expression between men and women?

*Inform the participant that, to allow more time for thought, the following questions on the meaning of pain will also be asked during the second interview.*

Knowing how your community views pain may help healthcare professionals to better know how to care for you.

2. Does pain have meaning or significance within your community?

- If yes, what is the meaning or significance of pain?

*Cues: Note positive or negative words, is it viewed as honorable? Is it viewed as having any benefits? Is it viewed as having any harms? Do others value it, ignore it*

- If the view of pain is that it's \_\_\_\_\_ (meaning from participant), what are the resulting actions that you would see in the community because of this view?
- Does your community view pain as having purpose? Once again, we are asking about this to help care givers give better care to women with chronic pain.
- If yes, what is this purpose?

*Cue: spiritual purpose? e.g. Being rewarded for it after death? Evil eye?*

Knowing how your community deals with pain may help us to know how to better care for you.

### 3. In the Afghan community, how do women deal with their chronic pain?

*Cues: Use of cultural remedies, healthcare access, management strategies e.g. stay at home & rest? Ignore the pain?*

*Participant may want to review the definition of pain management*

- Is there a difference in the way women take care of their pain based on level of education, generation, gender?
- How does pain affect women's physical activities?
- Which is most common, do you think? – dealing with pain by staying home and resting, or through movement and exercise?

## **Segment 2: Origin of Pain**

Anything that you share with me today will be kept confidential. Your name will not be shared with anyone outside of the research team.

### 4. What is the story of your pain experience? That is, what is the story of how your pain started and the journey until now?

- Have there been any significant changes in your pain experience from when it started until now? If so, please explain.

*Thank her for sharing her story!*

## **Segment 3: Symptomology of Pain (This segment uses Mixed Methods - Standardized Forms and Interview Qs)**

I want to learn from you about your health.

### *Complete Questionnaires*

- ✓ Pain Faces Scale
- ✓ McGill Pain Questionnaire
- ✓ Body diagram

➤ How have you expressed your pain?

*Cues: Who you tell, how you behave, gestures, body language?*

5. How do your pain symptoms affect you?

*Cues: May include how it affects Activities of Daily Living (ADLs) or Quality of Life (QoL), social activities, relationships, etc.*

➤ Have there been any changes to the way your pain has affected you from when it started until now? If so, please explain.

➤ Is there anything that provokes your pain, or makes the pain stronger?

*Cues: Activities, Positions, Emotions, Stress?*

I want to learn if there are better ways to help you with your overall health. Understanding your overall health may help health care professionals to know better how to care for you.

➤ Do you have any stress or emotional pain in your life?

➤ If so, does this have an effect on your physical pain? If so, how?

➤ How is your experience of pain similar to or different from how others in your Afghan community experience pain?

### **Segment 4: Management of Pain**

6. How do you deal with your pain?

*Cues: May include coping strategies, healthcare utilization, medications, cultural-specific management techniques, etc.*

➤ (if accessing healthcare) When it comes to healthcare, how do you decide where to go and who to see? How often to go? Whether to follow the advice or take the recommended treatments?

- Have there been any significant changes in the way you deal with your pain from when it started until now? If so, please explain.
- How is the way you deal with your pain similar to or different from how others in your Afghan community deal with pain?
- Do you feel that you have control over dealing with your pain?

I want to learn if there is anything that keeps you from doing a good job of taking care of your pain. What you share will be kept confidential.

7. Is there anything that prevents you from taking care of your pain well?

*Cues: May include time, money, cultural barriers to healthcare, etc.*

### **Segment 5: Last Remarks**

8. Would you like to share anything else that has not been discussed yet in this interview?

9. How are you feeling right now? (*Ensure that participant is comfortable with the content that was shared*)

*Thank her for her participation*

## Appendix E

### Short Form McGill Pain Questionnaire

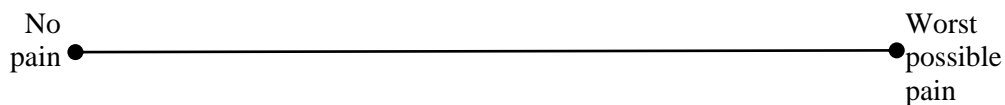
#### 1. Pain Rating Index

*Please rate your pain on a scale of none to severe (0 = no pain, 3 = severe pain) for each of the pain descriptions below.*

		None		Mild		Moderate		Severe
Throbbing	0		1		2		3	
Shooting	0		1		2		3	
Stabbing	0		1		2		3	
Sharp	0		1		2		3	
Cramping	0		1		2		3	
Gnawing	0		1		2		3	
Hot-Burning	0		1		2		3	
Aching	0		1		2		3	
Heavy	0		1		2		3	
Tender	0		1		2		3	
Splitting	0		1		2		3	
Tiring-Exhausting	0		1		2		3	
Sickening	0		1		2		3	
Fearful	0		1		2		3	
Punishing-Cruel	0		1		2		3	

#### 2. Present Pain Intensity

*Tick along the scale below to represent the pain intensity you feel right now.*



#### 3. Evaluative overall intensity of total pain experience.

*Place a check mark in the appropriate box to represent your overall intensity of pain over the last day.*

Evaluative		
0	No pain	
1	Mild	
2	Discomforting	
3	Distressing	
4	Horrible	
5	Excruciating	

## Appendix F

### Developing the Cultural Model of Pain Experience

Step 1. Identify factors that influence pain experience in the interview text.

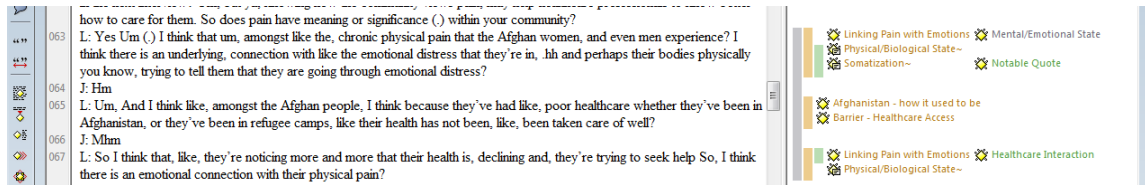


Figure F1. Coding interview text in Atlas.ti to identify factors that influence pain experience.

Step 2. Explore the relationships that exist between the factors that influence pain experience, using Atlas.ti networking tools (conceptual mapping).

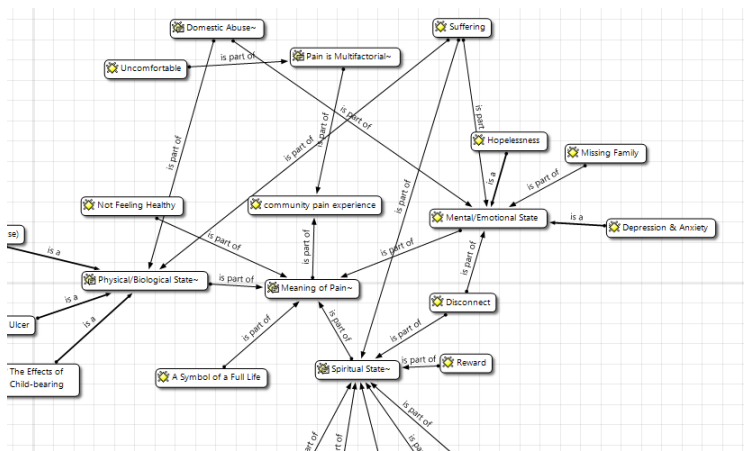


Figure F2. Exploring relationships using Atlas.ti network tools.

Step 3. Define the key factors in pain experience.

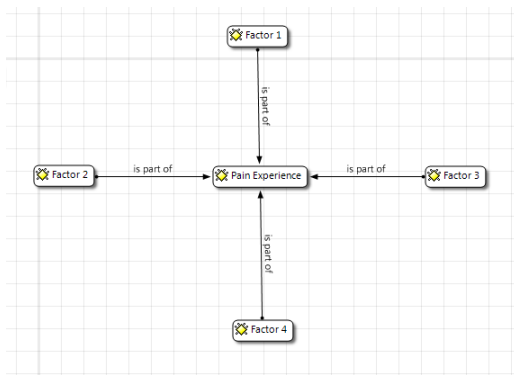


Figure F3. Defining key factors in pain experience, using Atlas.ti network tools.

Step 4. Clarify the relationship between key factors in pain experience.

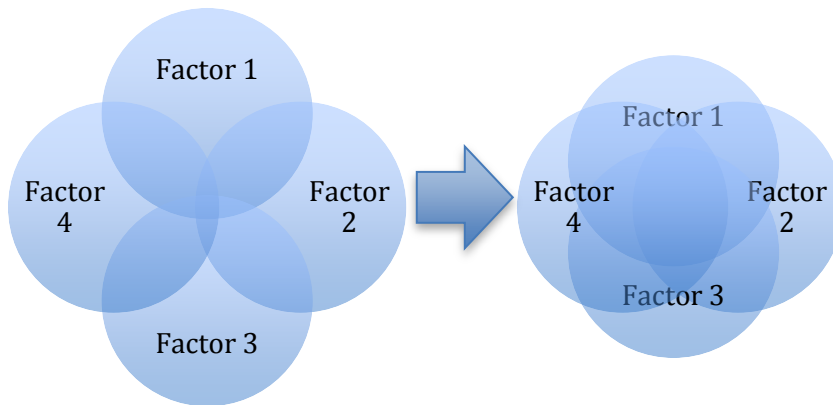


Figure F4. Clarifying the relationship that exists between key factors in pain experience.